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**Patients from lower socio-economic  
backgrounds who do not access  
cardiac rehabilitation programmes: A  
phenomenological journey**

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**A thesis submitted in partial  
fulfilment of the requirements of the  
University of Northumbria at  
Newcastle for the degree of  
Professional Doctorate in Nursing  
Sciences.**

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## **Abstract**

It has long been documented that patients from lower socio-economic backgrounds do not access health services. There have been Government led initiatives to ask service users what they want from services to provide initiatives that will improve the health and well-being of the population. There has been little or no involvement of patients who do not access services to ask them why they do not attend or involve themselves in decision making.

Previous studies into access to cardiac rehabilitation have been predominantly quantitative, with very little qualitative data to explore the reasons why people from lower socio-economic backgrounds do not access the programmes provided. In this study beliefs of people who have not accessed cardiac rehabilitation are explored with a group of participants who have a diagnosis of coronary heart disease using a Heideggerian phenomenological approach.

Semi-structured interviews were used to collect data. Themes were identified using line by line analysis. Three case examples were described bringing the data back together into a whole transcript for further exploration. The key findings from the research showed that the participants, all from the five poorest electoral wards of Darlington highlighted what to them were the significant factors in their health journey. The most common themes were (1) support, (2) choices and risks, (3) cardiac rehabilitation inhibitors and (4) perceptions of what had happened to them.

In conclusion the findings from this study can be used to stimulate a review of current thinking and practices among health professionals, educators and other agencies involved in supporting this group of individuals to meet their long-term adjustment needs. Long term cardiac rehabilitation provision could be further enhanced if future policy initiatives reflected the needs of this group of individuals, and further research into this area could be implemented.

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## **Declaration**

I declare that the work contained in this thesis has not been submitted for any other award and that it is all my own work. I also confirm that this work fully acknowledges opinions, ideas and contributions from the work of others.

Any ethical clearance for the research presented in this thesis has been approved. Approval has been sought and granted by the School Ethics Committee on the 20<sup>th</sup> April 2007.

**Name: Barbara Conway**

**Signature:**

A handwritten signature in black ink that reads "Barbara Conway". The signature is written in a cursive style with a large initial 'B' and a long, sweeping underline.

**Date: 14<sup>th</sup> June 2012**



# CHAPTER 1 GENERAL INTRODUCTION

## **1.1 Introduction to the study**

This chapter provides the background for the thesis and sets the scene, exploring the views of patients from lower socioeconomic backgrounds, their experiences of the services, and why they do not access phase three cardiac rehabilitation services, using a phenomenological approach (Heidegger 1962). The chapter includes the national perspective of cardiac rehabilitation and a personal view of the researcher's role and experience in the development of cardiac rehabilitation services. The aims and objectives of the study will be provided within this thesis chapter.

The study is a phenomenological health journey from the participant perspective and a research journey for the researcher. The background to the study provides the basis for the need for further research and prepares the reader for the study itself.

## **1.2 Research question**

The overall research question is:

*Why do cardiac patients from lower socio-economic backgrounds not access phase three cardiac rehabilitation services?*

## **1.3 Background to the research study - Setting the scene**

This section will explore the background from a national and personal perspective to set the scene to the research study. Policy drivers for the management of cardiovascular disease will be explained. A personal perspective of my job role will introduce the development of services within my area of work and the gaps that have shaped the need for this research study.

### **1.3.1 National Perspective**

Coronary heart disease, until 2010 was the biggest cause of death in Britain, now overtaken by cancer. Like all major illness coronary heart disease has physical, psychological and behavioural impacts on patients and their families, providing challenges for health care professionals involved in their care. The Government, in April

2000 produced the National Service Framework (NSF) for the management of cardiovascular disease with targets and milestones set out for a ten year period. Unusually for a NSF, money was allocated to its development, implementation and evaluation. Local organisations were required to produce action plans and develop services to ensure that the NSF was fully implemented by 2010. It is now ten years on, and this study highlights an issue that continues to challenge health care professions, the provision of phase three cardiac rehabilitation for people from lower socio-economic groups who traditionally do not access services.

The National Service Framework (NSF) for Coronary Heart Disease (April 2000) provided health professionals with prescriptive standards and targets for the management of coronary heart disease. Chapter seven of the document focused on cardiac rehabilitation, with standard twelve requiring:

*“NHS Trusts should put in place agreed protocols/systems of care so that, prior to leaving hospital, people admitted to hospital suffering from coronary heart disease have been invited to participate in a multidisciplinary programme of secondary prevention and cardiac rehabilitation. The aim of rehabilitation was to reduce their risk of subsequent cardiac problems and to promote their return to full and normal life” (NSF 2000)*

The framework calls for a tailor made service for patients, making services relevant and appropriate for all individuals who experience a cardiac event. Services should provide programmes of care that are specific, measurable, achievable, realistic and timely for patients following their event. This is key to this study, as the people from lower socio-economic groups are a challenge to health professionals providing phase three cardiac rehabilitation, with some unable to read, living in the poorest housing conditions, unemployed or in low paid work and more at risk of heart disease.

The accepted definition of cardiac rehabilitation is from the World Health Organisation. It reads:-

*“The rehabilitation of cardiac patients is the sum of activities required to influence favourably the underlying cause of the disease, as well as the best possible physical, mental and social conditions, so that they may, by their own efforts preserve or resume when lost, as normal a place as possible in the community. Rehabilitation cannot be*

*regarded as an isolated form of therapy but must be integrated with the whole treatment of which it forms only one facet” (WHO 1993).*

There are four stages of cardiac rehabilitation recognised through the British Association of Cardiac Rehabilitation (BACR), accepted nationally as the framework for practice. Phase one is the hospital admission, phase two is immediate post discharge (4-6 weeks), phase three is the intermediate stage (6-12 weeks) and phase four is long term maintenance (Coats et al 1995).

The policy drivers for coronary heart disease management and patient participation have been led nationally by the publications of the Department of Health of the Coronary Heart Disease National Service Framework (2000), The NHS Plan (2000) and the Health and Social Care Act (2001). The NHS Plan (2000) set out plans to establish a new system of patient and public involvement for England to replace the Community Health Councils, as part of the modernisation agenda led by the Labour Government. The system was also designed to respond to the Bristol Royal Infirmary Inquiry report (2001) recommending patient representation at every level of the NHS. According to the NHS Plan (2000), patients are the most important people in the health service.

The NHS Plan outlined reforms intended to give patients new rights and roles within the health service. In chapter 10 of the NHS plan, “Changes for patients” recommendations are set in place for patient and public involvement in the provision and design of health services. These provide health professionals with a policy to develop services but do not give direction on how to implement these changes within a society that is multi-cultural, socially and geographically diverse, and with differing resources available.

The Department of Health published policy guidelines ‘Strengthening Accountability: Involving patients and the public’ in section 11 of the Health and Social Care Act 2001. This Act took the NHS Plan forward in the Government’s commitment to making sure the NHS delivers patient-centered care. Other policy drivers outlined by INVOLVE, promoting public involvement in NHS, public health and social care research (2004) gave frameworks for further National policy drivers specific to public/patient involvement. These are ‘A first class service: Quality in the new NHS’ (1998), ‘Patient

and public involvement in the new NHS' (1999), 'A quality strategy for social care' (2000) and 'Shifting the balance of power' (2002).

The Department of Health publication "Addressing inequalities – reaching hard to hit groups" (August 2002) also supports the need for tackling inequalities in access to services. It called for improved access for socially deprived patients to access health services and early intervention strategies to be put in place. Ten years on from the publication of the NSF for Coronary heart disease this study will explore how relevant the issue is of involving patients from lower socio-economic backgrounds in the development of services.

Designing phase three cardiac rehabilitation services to suit all is an issue for health care teams so that programmes offer consistency and efficacy across the country. Some programmes are once a week, some twice a week, with a duration of between six to twelve weeks. The timing of rehabilitation is dependent on the resources of each area, with some areas providing single sex sessions, evening sessions or lay person led sessions. This study will contribute to the management of planning, developing, maintaining and evaluating cardiac rehabilitation services for people from all socio-economic groups.

Darlington has a population of 111,000 people, with 11 general practices. Of the 25 electoral wards, 5 are among the 10% most deprived in the country from the index of multiple deprivation, with a further 2 experiencing the same levels of deprivation for income and child poverty. A further 11 electoral wards are among the 10-50% most deprived wards nationally according to the index of multiple deprivation. Within the index of multiple deprivation there are 7 domains, (1) health; (2) education; (3) housing; (4) crime; (5) employment; (6) income and (7) environment (Fleming et al 2003).

All the GP practices in Darlington have a coronary heart disease register. All patients with a diagnosis of cardiovascular disease are offered a tailor-made phase three cardiac rehabilitation programme with a choice of location, either at the local district hospital or within the community. The programme runs twice a week for eight weeks and includes physical activity, lifestyle issues, relaxation, support and advice. A flowchart showing the patient journey through the stages of rehabilitation in Darlington can be found in

Appendix A. Patients are reviewed annually in a coronary heart disease clinic, facilitated by a practice nurse. Although incidence of the disease is similar across the town the average age of a person with coronary heart disease in the poorest electoral ward are 62, whilst in the most affluent electoral ward it is 75. Age is not a factor in the cardiac rehabilitation provision, with patients from all ages invited to the programmes. The youngest in Darlington has been 17, whilst the oldest has been 96 years old. Those patients with other health problems are not excluded, as a programme can be adapted to suit all the individual needs of the patient.

Prior to the NSF, community cardiac rehabilitation was not in place, and phase three cardiac rehabilitation programmes, provided within hospital settings, were sparse across the country. The NSF provided a framework on which to build innovative services within timescales and targets. In the following section is a summary of my personal perspective on developing my role and cardiac rehabilitation services.

### **1.3.2 Personal perspective**

This study is an academic journey for the researcher in her professional role. This section summarises the role she plays within her organization and how this has had an impact on her interest in developing services for people from lower socio-economic backgrounds. Her story is told in the first person to enable the reader understand her perspectives and experiences.

I was employed by the Primary Care Trust in April 2001 to facilitate and develop services outlined in the National Service Framework for coronary heart disease (NSF) for people with heart disease and their families. There was a cardiac rehabilitation service within secondary care, but I was required to complement this with a similar service based in the community in a venue that was within a low socioeconomic area of the town because participation was thought to be an issue for this group of patients. My role as specialist nurse for coronary heart disease and rehabilitation was a new role and I was given a broad remit of ensuring the NSF was supported and targets were reached.

The Community Cardiac Rehabilitation service began in October 2001. The service was initiated to provide rehabilitation for people with angina, pre and post cardiac surgery, myocardial infarction, transplants and congenital cardiac disease, and to complement

the current rehabilitation service at the local district hospital. The service in the community was the first of its kind in the country and needed careful facilitation in order to enable its success. Other parts of the country offered cardiac rehabilitation within a hospital setting for patients who had experienced a myocardial infarction; none offered rehabilitation for patients who had a diagnosis of angina or post-revascularisation.

Part of my role as specialist nurse for coronary heart disease and rehabilitation within Darlington Primary Care Trust was to develop, implement and evaluate the service, with the help of a committed team of nurses and physical activity specialists. The service has grown to be an effective service model used by others both in the United Kingdom and abroad. In 2003 we were finalists in the National Health and Social Care Awards for the 'Innovative and imaginative' approach to the management of newly diagnosed angina patients. The model offers patients who are newly diagnosed with angina a telephone call, offer of a home visit and a place on a community cardiac rehabilitation programme within 24 hours of discharge from the hospital. The programme is eight weeks long, twice a week, consisting of physical activity, lifestyle modification, relaxation techniques, information and support. It is facilitated by a specialist cardiac nursing team and a physical activity facilitator. The programme is supported with a cognitive-behavioural plan, 'The Angina Plan' (Lewin 1999) and a relaxation tape programme. The service was a pilot for the 'Angina Plan' and health professionals both within this country and abroad used our team as advisers and examples of good practice.

With a policy in place, the service was developed using evidence based and intuitive practice. Service users were consulted at all stages to provide a tailor made, menu based rehabilitation programme for people with all degrees of physical ability (Thompson 1995). These service users were patients currently on the cardiac rehabilitation programme within secondary care, and voluntary support group members who were instrumental in enabling the service to be initiated, to develop and progress. The evidence base was gathered from guidelines for cardiac rehabilitation for people who had experienced a myocardial infarction (Coats et al 1995) and a literature search was also conducted.

The literature search explored published research into cardiac rehabilitation and effective models of care. Unfortunately no evidence existed for rehabilitating patients

with angina, but evidence was adapted and adopted for the community cardiac rehabilitation service from the myocardial infarction and post surgical literature. Guidelines and protocols were developed and approved at Trust Board level. These are revised annually with the help of the team and the clinical governance department in the Primary Care Trust.

Intuitive practice also influenced the service. This came with the skills and knowledge I had acquired through twenty years of cardiac nursing, professional and personal development, and the varied experiences of other members of the team. Although experience does not necessarily equate with expertise, it is impossible to have expertise without the experience according to Easen et al (1996). He argues that intuition is an irrational process that has a rational basis. Often 'Gut feelings' (Pyles and Stern 1983) influence decision making. In the development of the service intuitive practice does exist among the team, not only on its own but within the confines of policies, protocols and guidelines. According to Bastik (1982) 'emotional involvement is central to all aspects of intuition', and this is the case with the rehabilitation service. As a team we discuss intuitive aspects of our work to promote patient well being and progress. The cardiologist and myself discuss case studies each month, and often intuitive clinical judgments are made based on the needs of the service user. I and my colleagues develop a very close relationship with the users and their families breaking down professional boundaries to provide a service that not only aims to be effective but enjoyable too.

Communication with other health professionals, voluntary groups and users was fundamental to the facilitation of service development. The rehabilitation team at the hospital was consulted at each stage of development. Encouraging new ways of cross trust working involved all from the cardiologist, GPs, nurses, community staff to the local Borough Council.

The phase three cardiac rehabilitation programme is provided as part of a group in a twice weekly, eight week programme with physical activity, relaxation and lifestyle management. It is held in a local sports complex in partnership with the Borough Council. The voluntary coronary support group provides monthly walks, and the cardiologist attends bimonthly to answer questions from the service users. Users who are unable to access this service are offered a one to one home based rehabilitation

over a twelve week period covering all aspects of their disease management. People waiting for procedures or surgery are offered a modified programme, with a carefully designed physical activity component either as part of the group or at home, this is known as the 'Get Fit For Your Op' programme.

As a facilitator of a new service it was necessary for me to reflect and learn as the rehabilitation programme was established, implemented and evaluated. Kolb's experiential learning model (Kolb 1984) argues that theory and practice grows in a continuous circle. This model encompasses my work as a facilitator. The concrete experience is the support, advice and guidance given to users of the rehabilitation service. On the basis of their experiences new ideas of service delivery are created and tested to improve their journey to good health through observation and reflection.

Reflective practice cannot be seen in isolation. A possible problem arising from this is that the practitioner focuses solely on his or her practice without consultation or concern for others. Reflective practice needs to be in partnership with reflexivity. According to Brechin et al (2000), reflexivity recognizes the practitioner and their communication with service users and others in the development of interventions. They must be aware of their own assumptions and values.

According to Barnett (1997) there are three domains of critical practice that have an impact on the work of health professionals. These are critical action, analysis and reflexivity, overlapping into critical practice. (See Fig. 1). As a facilitator I work across these domains. Within critical action I am concerned that my skill base is continuously upgraded through learning and experience. Eraut (1994) argues that as professionals we gain knowledge from both formal learning and practical experience, both bringing us into contact with new knowledge and ideas.

I work with users to empower them to take control of their well being before, during and after they have completed their cardiac rehabilitation. Encouraging users from all social and cultural backgrounds to access health services continues to be a challenge for all health professionals. Positioning the group programmes in a sports centre rather than a hospital tries to improve the rehabilitation uptake from all social groups. By offering a home based service the users have a choice not to attend a group if they are not able, or

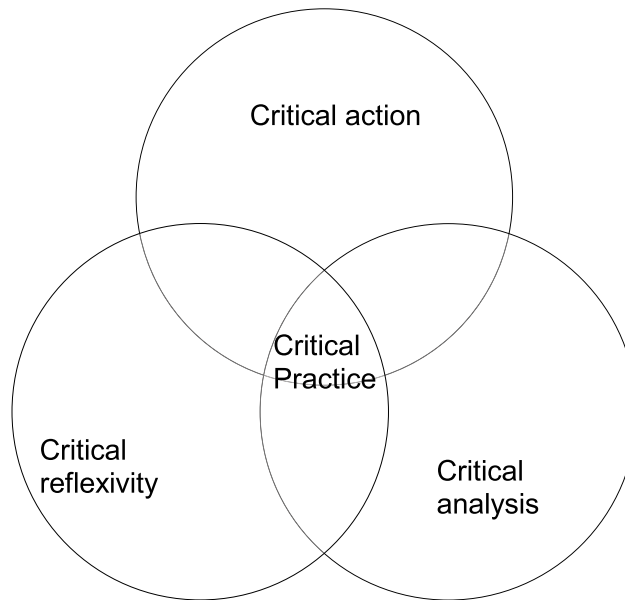


do not wish to. I use critical analysis daily in my work. The service is continuously evaluated and updated through regular literature searches, policy and guideline reassessment.

Database information is kept up to date and an annual report submitted to the trust board to feed back on the service progress. Users are invited to an annual focus group, complete satisfaction questionnaires and complete suggestion cards to impart their recommendations for the service. Regular operational reviews are held within the rehabilitation team to address local issues. The cardiologist, GPs and hospital staff meet regularly to discuss the service.

Critical practice is not a theoretical, time consuming exercise, it is essential to the development of new services and the success of these services to continue to be supported and funded at local and national levels of the NHS. My interest in critical practice was the foundation for this study. Health professionals in recent years ask patients what they want from services but sometimes fail to explore the needs of those who do not access health care. From the work I undertook to develop the community cardiac rehabilitation service I became aware that the patients and the voluntary group members were largely middle class, educated people who found the programme enjoyable and relevant. I wanted to explore the needs of the 'unheard' patients, those from lower socio-economic backgrounds to see if our services could be further improved to enable this group of individuals to understand the relevance of the programmes to their well-being.

**Fig. 1**



Three domains of critical practice (from Brechin, Brown and Eby 2000).

Developing a new service brings unknown challenges to the health professional. Although clinical knowledge is present, the skill of transferring this to service development requires a theoretical base that has the ability to be used in a practical way. Nevertheless challenges existed that affected personal and professional growth within the service. Within the National Service Framework for Coronary Heart Disease (2000) evidence based practice is a key strategy to improve the management of people with heart disease.

As a specialist nurse the boundary between evidence based practice and research often overlaps. Polit and Hungler (1987) define research as a systematic inquiry that uses orderly scientific methods to answer questions or solve problems. Sackett et al (1996) describes evidence based practice as “conscientious, explicit and judicious use of current best evidence in making decisions about the care of individual patients” (p.71).

Both these definitions have common characteristics when looking to develop practice, with much of the terminology used in evidence based practice derived from research.

The challenge set by the need for evidence based practice is discussed by McInnes et al (2001). She argues that evidence based practice can “encourage rigid and prescriptive practice” (p.40). Balancing the need for individual programmes of care for users and supporting the National Service Framework, whilst avoiding rigidity and prescriptive care is difficult in practice. Larrabee (2004) argues for a need to change practice through research to provide cost effective, high quality care for patients. Health professionals need to constantly keep up to date with current, effective practice to allow this to happen.

Clarke et al (1999) argues that health professionals who are involved in the development of practice are relative outsiders within the research field and in some cases marginalised by the research world. Although I have not experienced this myself, I nevertheless see the challenge to be conscious of research evidence to support the rehabilitation work I undertake. According to Small (2003) knowledge, not evidence should determine practice in Primary Care. Yet in a climate of litigation and accountability knowledge needs to be supported by evidence to promote credibility in the services we provide.

In order to facilitate the rehabilitation service effectively, communication skills are an important challenge. As health professionals we are always referring to ‘good communication skills’ and ‘good listening skills’, without fully understanding the processes involved. Cultural and social differences exist, affecting value and belief systems. According to Eraut (1994) communication needs to be tuned to person and context. He suggests that an effective communicator has a good knowledge of people and is able to read situations. Changes in the service need to be negotiated, and problems with individual users discussed. Liaison with voluntary and professional groups is essential.

There is a continuing tension between what employers want and what professionals think is required to develop practice. According to Brechin et al (2000), professional training and career progression is an uneasy alliance. There are the usual compulsory

courses on health and safety, Caldecott, fire and cardiopulmonary resuscitation. In order for services to grow the personal development of the health professional is important. A training policy exists at the Primary Care Trust where I work outlining what study leave will be provided and to whom. Professional and personal development continues to be part of my day to day working life, with personal development plans and appraisals important to personally develop within a growing organisation.

Following a service development it is important for facilitators to reflect on its success, but not to become complacent and develop the service no further. The community phase three cardiac rehabilitation programme is continuously changing and new services are being discussed and planned for the future. These include rehabilitation for people with heart failure, peripheral vascular disease and diabetes. Financial and human resources are always an issue for Primary Care Trusts, good relationships with the Trust Board is essential for promoting and furthering services in the community.

In 2004 I took on a new role as cardiovascular clinical team leader of a growing coronary heart disease and heart failure team. This role was in addition to my clinical role, and involves managing a specialist cardiac team incorporating human resource issues, leadership, strategic management and service development on a county wide scale. I also undertook leadership and management courses.

The NSF was a ten year programme to improve cardiovascular health within the population and it has now, in 2010 come to an end. National evaluation of the success of it and the challenges remaining are currently underway to evaluate the work that has been done nationally and locally and I have been involved in this process through interviews and questionnaires. In the future health professionals need to take cardiovascular management to the next level and keep developing services for people in the population and their families.

In conclusion the NSF has enabled organisations and individuals to develop services for people with cardiovascular disease and their families with a structured approach to care. New services have given patients quicker and more effective access to healthcare but challenges still remain. Although deaths from cardiovascular disease have been reduced by 40% in the North East, people still do not access all the services they are entitled to.

New cardiac rehabilitation services have been innovative and provided patients with a better choice of what services they want and the location. Despite the phase three cardiac rehabilitation programme in Darlington being successful, lessons remain to be learnt, and gaps filled to provide an even better opportunity to reduce mortality from cardiac disease, to increase uptake of cardiac rehabilitation and reduce hospital admissions. In this study I want to explore the issues facing people from lower socioeconomic backgrounds and their access to phase three cardiac rehabilitation services in order to understand their health beliefs, health needs and develop cardiac rehabilitation services for the future.

#### ***1.4 Aim of the study***

Using a phenomenological approach, delineate the barriers that exist for patients from lower socio-economic backgrounds accessing phase 3 cardiac rehabilitation programmes.

#### ***1.5 Objectives of the study***

- Using qualitative data from patient interviews explore the impact a diagnosis of heart disease has had on patients' perceptions and experiences of their care.
- To examine how patients' perceptions affect their decision to not take part in phase three cardiac rehabilitation.

#### ***1.6 Summary***

The national perspective of the management of cardiovascular disease and the personal journey for the researcher as a specialist nurse and clinical lead has given the impetus for the development of the study. The study will use a phenomenological approach to explore the experiences of people from lower socio-economic groups who do not access cardiac rehabilitation. It is hoped this study will have a local and national impact on the development of services for people with cardiovascular disease and their families for the future, post NSF. The research question, aims and objectives provide the framework for the study.

In the next chapter a literature review will explore published articles that support the research question and process. This will highlight research areas and methodology that have been studied previously and gaps in the knowledge base for further research potential.

## **CHAPTER 2 – LITERATURE REVIEW**

### ***2.1 Introduction***

The previous chapter provided an introduction to the study that included the research question to be addressed. To explore why patients from lower socio-economic backgrounds do not access phase three cardiac rehabilitation services a review of literature was undertaken before data collection and analysis. As a healthcare professional facilitating cardiac rehabilitation the researcher was involved in regular reviewing of the latest research and development into cardiac rehabilitation for service development and progression. The literature review determined the research question and design for this study.

The NSF for coronary heart disease has its roots in Darlington, with the catalyst being the death, at the age of 38 in June 1999 of a local newspaper photographer with a myocardial infarction. He died after waiting nearly a year to see a cardiac surgeon, inspiring the 'Chance to live' campaign by a local newspaper (Barron 1999). The Darlington MP, Alan Milburn knew the deceased and once he became Secretary of State for Health in October 1999 he ordered an immediate overhaul of cardiac services in England and Wales. He asked Professor Sir George Alberti, president of the Royal College of Physicians to chair the external reference group at this time. In 2000 Roger Boyle, a consultant cardiologist was appointed as the 'heart tsar' to take the groups evidence forward, following the publication of the NSF.

The literature search was commenced in 2004 and was regularly updated. All the searches used a number of bibliographic databases, these were: CINAHL, SOCIOFILE, PsycINFO, and MEDLINE PLUS from 1990-2010. The following key words were used: cardiac rehabilitation, access to cardiac services and socioeconomic factors, heart disease, myocardial infarction, angina management and heart surgery. Journals relating to nursing, cardiology, medicine and public health from 1990-2010 were also searched.

After the findings were explored in this study a further review of the literature was undertaken to update it. This was a general review of studies into access to cardiac

rehabilitation services. The review was extended to look at research articles that were not directly involved with cardiac rehabilitation but of possible relevance to the study.

## ***2.2 The evidence base for the National Service Framework for coronary heart disease (NSF)***

The NSF evidence base was explored to support the study. The NSF was published as a blueprint for tackling heart disease in England and Wales, aiming to reduce premature deaths from the disease by 40% over the ten year period. It was part of the Labour government's commitment to transform the NHS and provide "faster, fairer and more convenient" service for patients (Millburn 2000, NSF P.2). It recognised that heart disease was the biggest cause of premature deaths, particularly in those individuals from more deprived areas, with health care better in more prosperous areas. It was prepared by an independent expert group who set out standards and targets that should be met over a ten year period by health professionals across primary, secondary and tertiary care, involving ambulance services and the voluntary sector in achieving the goals set out in each of the seven chapters. The chapters were (1) Reducing heart disease in the population; (2) Preventing heart disease in high risk patients; (3) Heart attack and other acute coronary syndromes; (4) Stable angina; (5) Revascularisation; (6) Heart failure and (7) Rehabilitation. A further chapter was added in 2005 for arrhythmias and sudden cardiac death. For the purpose of this examination of the evidence base, concentration will focus on chapter seven, rehabilitation.

The NSF for coronary heart disease was developed using a medical model, secondary prevention being the priority. Despite it's strong clinical bias it became the basis for developing cardiac services across the country. It would transform care for patients with coronary heart disease within its ten year timescale. Although prescriptive, with milestones and targets it allowed trusts and PCTs to develop the services in an imaginative way that could be adapted for the patient's environment. Sharing good practice was encouraged across the country. National audit systems were developed to accurately measure the outcomes from the NSF, including the MINAP project that counted the amount of patients who had a myocardial infarction.

A public health or social care model would more likely have developed programmes of care focused on long term prevention of cardiac disease. The NSF did try and include



some public health strategies in standards one and two, reducing heart disease in the population. It asked that the NHS worked with partner agencies to develop, implement and monitor policies that reduced the prevalence of heart disease risk factors in the population. Men and women from social classes iv and v were more likely to have high blood pressure and eat smaller amounts of fruit and vegetables than those in social classes I and II. They were more likely to experience poverty during childhood, live in poor housing, be unemployed or in low paid work (Sharp 1998, Acheson 1998).

The milestones for preventing heart disease in the population were to develop health improvement programmes that reduced smoking, promoted healthy eating, increased physical activity and reduced obesity. The milestones were audited using quantitative data, with local health communities implementing plans to evaluate their progress against national targets associated with the white paper, "Saving lives: our healthier nation" (1998).

The evidence base for the cardiac rehabilitation chapter of the NSF was quantitative, based on national surveys, randomized control trials and reviews. The basis for the dietary recommendations was based on the Lyon diet heart study in France (De Lorgeril et al 1997). This study advised the adoption of the Mediterranean diet as a basis for a healthy diet. Using a foreign study on diet is an issue, given that no dietary studies were evidenced from England or Wales. The incidence of heart disease in France is low compared to Britain but diet may not be the only factor. Environment, climate and standard of living are not taken into account. There was input from psychologists who described hospital anxiety and depression scales, and quality of life measurements that were recommended to be used by health professionals to measure patients' psychological status consistently across the country.

By generalising from specific studies into national policy, key issues are raised and acknowledged by the NSF. The use of research studies as a basis to guide clinical practice can be random and inconsistent. One reason for this is the amount of medical literature available, more than two million bio-medical articles published in over 25,000 journals. Identifying and interpreting all the relevant articles is time-consuming and complex. As new research findings are constantly emerging, they can soon become outdated. The use of systematic reviews can assist the process as they are updated

regularly and include the most up to date and relevant data. Two sources of reviews were used by the NSF. These were the Cochrane collaboration reviews of tobacco, stroke, peripheral vascular disease, heart disease and effective practice and organisation of care. The second review source was 'Clinical evidence', a six monthly, updated compendium of evidence of the effects of common clinical interventions. It searches the literature and summarises the best available evidence and where there is no evidence it says so. It is a joint project between the BMJ (British medical journal) and the American College of Physicians. It does not overcome the issue of generalisation and transferability of evidence from one country to another but allows health professionals to examine evidence that supports their work.

The NSF political drivers focused on quantitative data with no qualitative evidence included. It was based on national audit data that was inconsistent and at times flawed. Each trust had individual data collecting systems and there was no national information technology system in place. The NSF encouraged the use of national audit systems with agreement of what was to be collated. As well as the MINAP system, national cardiac rehabilitation datasets were developed by the University of York.

The NSF was the beginning of a systematic approach to improving outcomes for people with heart disease, developing health improvement programmes. It had been published and initiated in a short timescale to address the management of coronary heart disease over a ten year period. It put in place systems that enabled health professionals to improve access to services, service provision and auditing across England and Wales.

The scope of the NSF was to provide evidence based practice that was both practical and flexible. It set out national standards, provided service models and established goals with performance indicators against which progress could be measured. It encouraged partnership working with a wide range of people from different agencies who would each play a part in achieving the goals set. People working in social services, public health, primary care, hospital settings, voluntary agencies, local authorities and education were all included.

### **2.2.1 Chapter seven, cardiac rehabilitation requirements**

The aim of chapter seven in the NSF was to set out “how the NHS and others can best help people who have had a heart attack, revascularisation or other cardiac event maximise their chances of leading a full life and resuming their place in their community” (NSF chapter seven, p.2). The NSF required that health professionals should provide skilled support that was tailored to each individual’s needs to enable them to make a full physical, psychological and emotional recovery. This support included help to make lifestyle changes such as smoking cessation, healthy eating and improving physical activity. Patients should be included in cardiac rehabilitation as soon as possible following admission to hospital and continued through the four phases until they are discharged and able to resume a normal life.

Patients following myocardial infarction, before and after revascularisation, with stable angina, with heart failure or following other interventions such as heart transplant should be included in the programmes. Those patients with unstable angina should be excluded. At the time of the NSF publication there were variations in provision around the country, with significant inequalities in the way people access the services. There were barriers acknowledged in the NSF that prevented a persons’ participation in cardiac rehabilitation. These included a lack of motivation, practical problems such as transport and a lack of appropriate provision, especially for women and those from ethnic minorities (Thompson et al 1997).

The NSF called for NHS trusts to provide effective interventions, with cardiac rehabilitation being integral in the care of the cardiac patient. They required health professionals to offer good quality cardiac rehabilitation to cardiac patients before discharge from hospital. The investigations and interventions that should be carried out on each patient were highlighted for each phase of their recovery. For phase one these were (1) Physical, psychological and social needs assessment; (2) patient held record;(3) lifestyle advice; (4) medication prescription with advice on each; (5) involvement of carer; (6) information about cardiac support groups and (7) provision of written information about cardiac rehabilitation. For phase two the health professionals were also required to (1) assess cardiac risk prior to a structured rehabilitation programme and (2) offer resuscitation training for family members. At phase three there was also a requirement to provide structured exercise sessions to meet individual needs.

Phase four was about the long term maintenance of lifestyle changes with included long term follow up in primary care with patients attending an annual review of their cardiac status.

The NSF was a systematic approach to cardiac care and came with significant funding for trusts to plan, develop and evaluate cardiac rehabilitation. It wanted a long term solution to cardiac rehabilitation provision encompassing quality patient care for people with cardiac disease, lifelong learning for patients and health professionals underpinned by clinical governance that was nationally adopted under local guidelines and protocols.

### **2.2.2 Exploration of the evidence base for chapter seven, cardiac rehabilitation**

The evidence base for chapter seven, cardiac rehabilitation was based on publications nationally. These provided the quality framework for developing the NSF and gave credence to the requirements. This section will explore some of the evidence and its influence on cardiac rehabilitation provision.

Prior to the publication of the NSF, the British Cardiac Society published joint recommendations on the prevention of coronary heart disease in clinical practice (Wood et al 1998). These were based on evidence from previous controlled trials into the effectiveness of lifestyle and therapeutic interventions in reducing cardiac risk. The recommendations were developed to bring together the European societies of cardiology, atherosclerosis and hypertension in collaboration. Until this time each society published their own separate guidelines on coronary prevention (British cardiac society 1987), management of hyperlipidaemia (Shepherd et al 1987; Betteridge et al 1987) and hypertension (Sever et al 1993). By bringing together the various societies it was hoped to provide a more unified and effective approach to the management of CHD. To achieve this, the joint recommendations asked hospital and primary care health care professionals to coordinate and provide an integrated strategy for patient care, a precursor to the NSF's similar aims.

The joint British recommendations lay down objectives and priorities for CHD prevention and secondary care management of patients with CHD. It outlined measurements of cardiac risk, lipids and blood pressure, whilst giving advice on how to improve lifestyle change with smoking and physical activity. It also recommended consistent first line

medical management of the cardiac patient. All these were adopted as the baselines and requirement of the NSF, with the added bonus of financial support to ensure they could be implemented in a systematic way.

In 1998 the NHS centre for reviews and dissemination published an effective health care bulletin about cardiac rehabilitation which influenced the NSF with its recommendations. The bulletin argued that cardiac rehabilitation promoted recovery, better health and reduced the risk of death from CHD in people with the disease. It recommended a physical activity component, psychological measurement and support and the need for services to meet the needs of all groups, including women, the elderly, ethnic minorities and people with all types of heart disease. This was used within the NSF to influence the targets and goals set for the implementation apart from the elderly. When the NSF was published it was developed as a service for people under 75. Soon after its publication, the NSF for older people was published (2002) which called for all services to be provided for all ages. Local NHS trusts changed their policies and guidelines to reflect this and cardiac rehabilitation was offered to all patients, irrespective of age.

The bulletin was based on systematic reviews carried out on cardiac rehabilitation. The evaluation of literature was challenged due to the variability of interventions, patient populations studied, methodological issues and in some cases poor quality reporting. Most of the studies only explored people who had experienced a myocardial infarction who were low risk, male, white and middle-aged (Hill et al 1992; Wenger et al 1995; Duryee 1992; Mullen et al 1992; Picard et al 1989). Current provision of cardiac rehabilitation was explored within the bulletin. It found that service provision failed to meet the national guidelines for cardiac rehabilitation and secondary prevention measures were not always applied (Thompson et al 1997; Campbell et al 1998).

The effective health care bulletin on cardiac rehabilitation found that most phase 3 cardiac rehabilitation programmes were hospital based and offered only to low risk patients who had experienced a myocardial infarction (Campbell et al 1996; Davidson et al 1992). Although women accounted for a third of CHD patients they were less likely to receive cardiac rehabilitation according to a survey of 244 programmes in the UK that the bulletin authors explored (Thompson et al 1997). Most of the programmes were

exercise-based, usually providing group aerobic sessions once a week for 6-10 weeks (Campbell et al 1992), with 70-80% offering patient education (Campbell et al 1996).

The evidence base for the cost effectiveness of cardiac rehabilitation was included into the NSF to justify its appropriateness, benefits and effectiveness as a viable treatment plan. Taylor and Kirby (1997) explored systematic reviews on 22 trials of exercise based cardiac rehabilitation programmes. They argued that phase 3 cardiac rehabilitation reduces serum lipid levels, increased exercise tolerance, better psychological well-being and reduce mortality in post-myocardial infarction patients by 20-24%. The costs of each programmes varied nationally due to venue provision, cost of staffing and resources available. Oldridge et al in their randomised controlled trial of cardiac rehabilitation performed a cost analysis, finding the average cost for an 8 week; twice weekly programme was £360 per patient. In 2010 the BACR (British Association of Cardiac Rehabilitation) estimated the average to be £567 per person (Department of Health 2010).

Dietary considerations were explored in the development of the NSF. The main contributor was the Lyon diet heart study (Logeril et al 1999). This was a randomised secondary prevention trial exploring the benefits of a Mediterranean style diet in reducing the rate of recurrence after a first myocardial infarction. The study concluded that the protective effects of the Mediterranean diet lasted up to four years following a myocardial infarction. This resulted in the Mediterranean diet being recommended in the NSF for cardiac patients.

Exercise and cardiac rehabilitation trials established the benefit of exercise on cardiac patients. O'Connor et al (1989) examined 22 randomised trials to show a significant benefit of rehabilitation after myocardial infarction. Within their overview they reviewed total and cardiovascular mortality, sudden death, and fatal and non-fatal re-infarction. They found a 20% reduction in all fatality, with benefits for up to 3 years.

Since the publication of the NSF the Healthcare commission has monitored the progress of the targets, milestones and goals. In 2005 it published its report "Getting to the heart of it" to evaluate the NSF half way through its implication. Although many standards had been met recommendations were made for each chapter of the NSF for improvement. It

argued that cardiac rehabilitation progress had been slow. There was no evidence that more patients were being offered cardiac rehabilitation and barriers to access still existed. Audit data and monitoring was spasmodic and needed further work. They recommended investment in cardiac rehabilitation services.

The NSF gave healthcare providers a prescriptive framework on which to build effective, consistent cardiac services nationally. It gave clear goals and targets and was released with the resources to enable healthcare professionals to provide services. The main limitations of the initial NSF publication were (1) Patients over 75 year were not included; (2) It did not include patients with unstable angina or who had undergone valve surgery and (3) It said what needed to be achieved but left the design of services to the individual trusts.

In 2010, ten years post publication most areas nationally have achieved their targets and standards for cardiac rehabilitation, with the North East reducing mortality by 40% over the ten year period. Data is collected nationally and reported by the British Heart foundation. It shows that the North East of England has the greatest uptake for phase three cardiac rehabilitation programmes in England, 50%, London has the least, 27%.

Although the NSF has contributed to the reduction in mortality by developing cardiac services, and enabling effective measuring and auditing of data on a national scale other considerations need to be explained. The behaviours influencing the incidence of coronary heart disease are complex, multiple and influenced by a number of interventional strategies. The growth of public health strategies have had a long term impact on the reduction of cardiac disease that cannot be seen in isolation but in partnership with the work of the NSF.

Smoking is a significant risk factor for developing heart disease. The increase in smoking cessation services with free nicotine replacement therapy and cognitive behaviour support has had an impact on the number of smokers in England and Wales. The introduction of smoking bans in public places and increased taxation on cigarettes has also had a positive influence.

Other risk factors for heart disease have seen new services developed. Hypertension management in general practice has become part of the payment of GP services so more primary hypertension clinics have developed over the years. There have been public health initiatives for healthy eating such as 'Change4life' and obesity clinics established to tackle dietary risk factors. Media coverage by the British heart foundation has focused attention on recognising heart disease symptoms and the management of risk factors. Over the last ten years there has been an improvement of the monitoring and management of diabetic patients within primary and secondary care. GP practices now have a duty to provide primary prevention strategies as part of their contract. They are required to provide over 45 check ups on their practice population, checking blood pressure, cholesterol, thyroid function and glucose. They are identifying risk factors such as family history as part of their contribution to the reduction of heart disease and other long term conditions.

### ***2.3 Overview of literature into cardiac rehabilitation and socioeconomic factors***

Despite the potential and well documented benefits of structured cardiac rehabilitation programmes a significant proportion of patients fail to attend (Petrie et al 1996). Previous research over the last 10 years has focused on efficacy of rehabilitation programmes for people who have had a myocardial infarction or coronary artery bypass surgery. Qualitative research into the reasons why people from lower socioeconomic backgrounds do not access services and their beliefs of cardiac rehabilitation is limited.

Socioeconomic factors have been cited in many studies as a possible barrier to access to programmes, but little focused research in this area has been undertaken. (Wyer et al Earll 2002; Thow et al 2002; Higginson 2003; Cooper et al 2001) All the studies included have examined patients post myocardial infarction, few explore post surgical patients and none studied angina or revascularisation patients.

The outcome of a coronary event on an individual's quality of life and future survival has been explored in relation to lower socioeconomic groups (Morrison et al 1997). The outcome measures were the rate of coronary events, number of participants reaching hospital alive, the number of deaths in admitted patients and within the community. The results showed that event rates increased with age. The socioeconomic gradient reduced with age and was steeper in women than in men. The proportion treated in



hospital decreased with age and was associated with an increased level of deprivation. Morrison et al in their qualitative study concluded that socioeconomic deprivation affects not only death rates from myocardial infarction, but also an increase in event rates and chance of admission. Morrison et al leads this study to provide a qualitative platform for participants to relate their experiences of both the cardiac event and their subsequent journey. This enables the researcher to further explore the concept of socioeconomic deprivation, health outcomes and health beliefs.

Pell et al (1996) in their qualitative study aimed to determine whether deprivation affected the uptake of cardiac rehabilitation after a myocardial infarction. The participants' age, sex, postcode, co morbidities and consultant were recorded. The analysis showed that the uptake of and completion of cardiac rehabilitation was significantly associated with deprivation. The authors concluded that further study was needed to ascertain the reasons why patients from deprived areas were less likely to attend or complete programmes in order to improve the uptake of this service. Pell et al provides the impetus to ask patients who do not access services the reasons for their decisions. Choosing patients from lower socio-economic backgrounds for this study as the sample group will explore some of the issues highlighted by Pell et al.

A study by Lane et al (2000) compared a group who attended cardiac rehabilitation and a group who did not. They found non-attendees lived in more deprived areas and less likely to have paid employment. They had more symptoms of anxiety and depression. The study concluded that strategies were needed to encourage greater attendance among those not in paid employment from deprived areas. Melville et al (1999) found that social deprivation was the only factor that was significantly associated with poor uptake of cardiac rehabilitation. For this study it was decided not to compare those who attended with those who did not, as the research question is focusing on the non-attendees only. This enables this study to provide a more in-depth exploration about patients' views and beliefs.

The influence on whether socioeconomic factors affect a persons' decision to attend cardiac rehabilitation has also been studied in relation to their immediate post cardiac experience. Cooper et al (1999) argue that attempts to identify socioeconomic predictors of non-attendance to cardiac rehabilitation have not been successful. The study aimed to

show that illness beliefs held during hospitalisation, by patients who had experienced a myocardial infarction or post coronary artery bypass surgery could predict attendance on a rehabilitation programme. The authors concluded that 40% of the subjects attended cardiac rehabilitation. They found no differences in illness perceptions or socioeconomic variables between the diagnostic groups. Cooper et al in their quantitative study measured the illness beliefs of patients during their stay in hospital but did not effectively show a relation to socio-economic factors. This study will explore illness beliefs and illness perceptions in the sample group to establish a relationship between beliefs and perception and socially deprived individuals.

Rayer (1996) argued that the NHS has 'institutional ageism', with 33-50% of rehabilitation programmes having an upper age limit. None of the studies have explored the reasons why patients from deprived areas do not access services or do not complete the programmes. This study will not focus on age as a determinant of individuals' choice to not attend cardiac rehabilitation from an upper age point of view, but will further contribute to the research by exploring their beliefs about rehabilitation being designed to suit particular ages. In-depth study of the patients' perspectives is needed to enable services to be appropriate for their needs and those of their carers.

Only two qualitative studies into socio-economic factors were found during the literature search. Tod et al (2002) wanted to seek to identify health service use and access inequalities, and to suggest interventions to achieve a better capacity for the demand for cardiac rehabilitation services. The study used framework analysis techniques to study the results gathered from semi-structured interviews. Patients who had angina were not included. The authors found that patients from lower socioeconomic areas had more complex needs regarding their recovery.

Barriers to accessing services affected people from lower socio-economic groups (Tod et al 2002). The main barriers were information, support for partners and their families, waiting lists for the rehabilitation, appropriateness, communication systems, and understanding of coronary heart disease and the benefits of rehabilitation. Some patient subjects found group programmes unappealing, location of the programmes and transport difficulties or parking problems an issue. The study did not include patients from ethnic minority backgrounds, despite this group tending to come from deprived

areas. Wyer et al (2001) explored what influenced people in attending cardiac rehabilitation. They found that attendees were more likely to see themselves in control of their recovery and non-attendees used avoidance or minimizing coping strategies.

The literature review papers gave an overview of predictors for attending rehabilitation. They concluded that socio-economic factors and medical factors influenced a persons' willingness to attend rehabilitation. This study will support the previous qualitative studies and highlight new issues for the socially deprived individuals participating in the study. It will not be gender, age or race specific, but include participants who live within the five poorest electoral wards in Darlington.

The understanding of the complex needs and social expectations of socially deprived patients needs further study in relation to the appropriateness of programmes for them. This group of patients are often in poor housing, low paid employment or unemployed. They can be socially isolated with little or no social support, reluctant to seek help from health professionals or access services that they do not see as relevant to themselves. Physical barriers to accessing cardiac rehabilitation such as transport, age and cost that exist for socioeconomically deprived patients are known, but in-depth study has not addressed this from the patients' perspectives.

Some of the findings in previous research that have emerged from this part of the review have an influence on this study. Previous research has shown that socioeconomic factors affect rates of coronary heart disease, admissions to hospital and deaths from the disease. National audit data shows a higher incidence within poorer socioeconomic areas across the country, with uptake, attendance and continuation of cardiac rehabilitation reduced in deprived areas. Transport systems are not always in place for patients from deprived or rural areas.

The verbal and written quality of the information given to cardiac patients and their understanding of this information deters socioeconomically deprived patients from attending or continuing cardiac rehabilitation. The appropriateness and benefits of programmes are not always seen by these groups. The understanding of their disease and the factors that affect them is made difficult when written and verbal communication is not tailored to individual patients' educational level. The support patients and carers

perceive they will receive in rehabilitation programme influences their uptake of programmes, particularly in the socially deprived groups. Waiting lists and the length of time a patient has to wait to attend rehabilitation affects the uptake of the service, particularly in the participants from lower socioeconomic groups. Patients from lower socioeconomic backgrounds in low paid work do not receive the same sickness benefits as those in better paid employment, and need to return to work as soon as possible to support themselves and families.

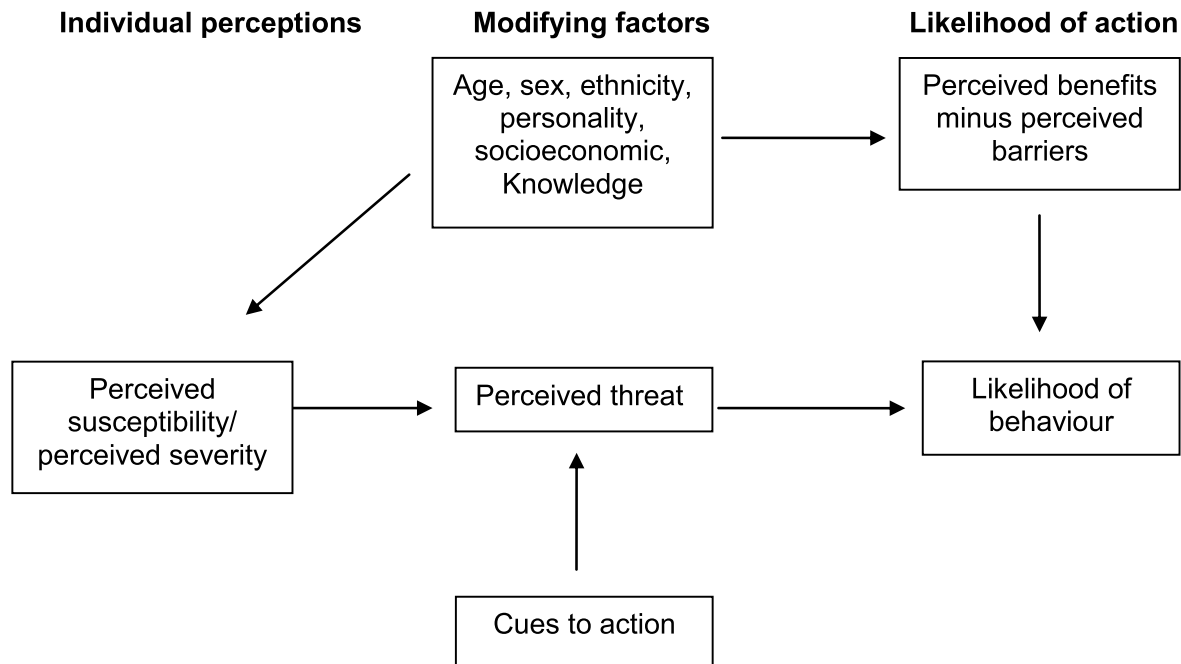
#### ***2.4 Other Literature relevant to the study***

After the review into cardiac rehabilitation and socioeconomic factors the literature review was extended into other areas relevant to the study. This part of the process was facilitated throughout the interview stage of the study, generated by what the participants expressed as issues for themselves. Based on the research focus of the study this part of the review has been divided into six major areas of concern. They are (1) perceptions about cardiac events; (2) coping with cardiac events; (3) lived experiences; (4) social support and (5) patient involvement in decision making. The literature review was broadened to look at cardiac rehabilitation research in a more holistic way and to include literature that had an impact on this study.

##### **2.4.1 Perceptions about cardiac events**

Illness perception is an important factor in this review. Exploring the beliefs that individuals use about an illness enables the experience to be understood and have meaning for them. These beliefs provide information about a persons understanding, emphasis and concern about their illness (Clark et al 1998). They also help in determining how an individual responds to the illness and their recovery and adjustment (Hampson et al 1990). The health belief model (Hochbaum 1958) provides a framework to understand how personal perceptions are influenced by a whole range of interpersonal factors affecting health behaviour as shown in Fig.2.

**Fig. 2 The Health Belief Model**



*Source: Stretcher, V. and Rosenstock, I.M. (1997) The Health Belief Model.*

There are four perceptions that form the main components of the model; (1) perceived seriousness; (2) perceived susceptibility; (3) perceived benefits and (4) perceived barriers. The perceived seriousness or severity of a disease on individuals' perceptions is often based on medical information or knowledge, but may also come from beliefs a person has about the difficulties a disease will create or the effects it will have on their everyday life (McCormack-Brown 1999).

The perceived susceptibility to personal risk is one of the more powerful perceptions in promoting an individual to adopt a healthier behaviour, with the greater the perceived risk, the greater the likelihood of individuals' engaging in behaviours that decrease the risk. The perceived benefit is the individuals' personal opinion of the value or usefulness of a new behaviour in decreasing the risk of developing or worsening a disease.

The perceived barriers to change is a persons own evaluation of the obstacles they may encounter when adopting a new behaviour. Of all the components of the model the perceived barriers are the most significant in determining behaviour change (Janz and Becker 1984).

According to Leventhal et al (1984) in their illness perception model people evaluate their health threats by constructing their own representations or perceptions of their illness, influencing their coping and adjustment. Cooper et al (1999) found that firm beliefs about cardiac illnesses have already been fixed, long before a personal experience of the illness, through knowledge gained from the media, or from the cardiac experiences of friends or acquaintances. Lewin (1999) suggests that patients' beliefs about heart disease are important determinants of their disability and quality of life, and resources should be invested to address and correct these at an early stage of the illness.

Most research into an individuals belief or perception of cardiac disease is based on the Leventhal and Nerenz self regulation model (1985). This model argues that individuals usually look for causes or reasons for their illness to understand, predict and control the perceived threat that was created as a result. This, in turn influences the individuals' management strategies for dealing with their stressful situations. It is based on five key dimensions of identity, cause, timeline, consequences and cure or control. Identity is the label the individual uses to describe the illness and the symptoms as being part of the disease. Cause relates to personal ideas about the cause of the illness. Timeline is the duration the person believes the illness will last. Consequences deal with the expected effects and outcomes of the illness. Finally cure or control is the amount of time it takes for the individual to recover from the illness.

There is a relationship between illness perception and depression. Grace et al (2005) explored this relationship with 661 patients diagnosed with acute coronary syndrome. The type of diet, heredity and stress were perceived to be the most influential causes of cardiovascular disease. Prevalence of depression was found to be greater in the younger patients. The study found that men showed they had greater personal control and found their treatment appropriate, but their depressive symptoms were related to

lack of physical activity and a reluctance to engage in exercise. The study concluded that illness perception had a direct relationship to depressive symptoms.

The belief by an individual that they can take control of their illness has a significant impact on the psychosocial adaptation and recovery following a cardiac event (Younger 1993; Johnson and Morse 1990). The perception of feeling in control rather than being in control has been suggested to be more powerful in motivating individuals to overcome the challenges of their illness, with positive psychosocial outcomes.

Moser and Dracup (1995) explored the relationship between feelings of being in control and psychosocial recovery, and to determine any difference between men and women. It was carried out on 176 individuals who had previously had a myocardial infarction or coronary artery bypass surgery, using a control attitude scale, psychological adjustment to illness, multiple affect check list and a socio-demographic questionnaire as the data tools. There were no significant differences between the men and women. They found that the higher the perceptions of control the more positive impact on psychosocial recovery. They concluded that it was possible to predict patients at risk of psychosocial distress from their cardiac event by assessing their levels of perceived control.

Severity of a cardiac illness has been argued to have a deciding factor in the recovery and adjustment of individuals to their illness. Nau (2005) explored the difference on how both sexes perceived the severity of their cardiovascular disease (myocardial infarction and unstable angina). They found that women do not perceive the severity of their illness any worse than men, even when clinical measures showed contrary results of perceived severity. The study concluded that despite their greater functional disability because of their illness, women were stronger than men, raising concern about the variation in care-seeking behaviour and treatment decisions between the sexes.

Socio-economic variations between affluent and deprived areas have been studied in a community based qualitative study by Richards et al (2002) to explore their effect on individuals' perceptions and behaviours towards their experience of chest pain. Individuals who lived in a deprived area showed increased vulnerability to heart disease, normalising their symptoms or confusing the pain with other possible conditions. These individuals suffered self blame, felt guilty for overusing medical services and avoided

medical help for fear of being reprimanded by their general practitioners. In contrast those individuals from affluent areas were more likely to deny any family history of heart disease, distancing themselves from being cardiac candidates. Their relationship with their doctors was however better, sharing scientific knowledge. The study concluded that decisions that patients took in response to chest pain was related to family and social norms about ill health, past experiences about ill health, and health care systems. Their perceptions of symptoms and illness were shaped by social and cultural factors rather than by gender.

In her study, Cornwell (1984) explored the lives of working class people living in East London. She used qualitative research to look at the feelings, beliefs and values of participants. She found that the dominant conceptions of health and illness are medical, with lay people having problems defining what they mean by “health” and “being healthy” (page 145). She argues that this difficulty is due to Western medical definitions of health are always based on an absence of disease. This study provides the reader with an insight into the public and private accounts of illness and health. The two types of account were distinctive for differences in their form. Public theories referred to ‘they’ meaning the medical profession as in ‘they say’, or ‘they know’, put forward in an assertive way, whilst private theories appealed to no other authority than that of the participant or a relative. Private theories were suggested rather than asserted. This shows the power and control lay people perceive the medical profession has. Their private theories were much more hesitant and unsure as it came from them and not an ‘expert’ source.

Peoples’ perceptions of their illness and what has happened to them during and following a cardiac event is an important factor in the study of feelings, beliefs and values. The literature highlights perceptions of illness as an important dimension, not just for cardiac patient but all those living with a long term condition.

#### **2.4.2 Coping with cardiac events**

Cardiac illnesses are stressful life events that lead to major threats and disturbances to the stability of individuals (Bennett 1992; Lesperance et al 1996). The ability to cope effectively with such events has been shown to be essential in establishing control over the situation (Johnson and Morse 1990) which in turn can influence how individuals



manage their illness. Coping has been defined as the ongoing process to manage specific external and/or internal demands (Lazarus 1996), and understanding and dealing with demands in their lives (Pargament 1997). This involves various cognitive efforts to appraise the situation appropriately, and develop strategies that would bring a person satisfactory outcomes and well being.

Lowe et al (2000) in their six month study examined the concurrent and prospective relationships between coping, emotional outcomes and perceived health in 128 individuals who had experienced their first myocardial infarction. They found a hierarchy of coping strategies that participants had used to deal with their myocardial infarction. Acceptance-focused coping was most commonly used, followed by problem-focused and social/emotion focused strategies. Avoidance-focused coping was shown to be the least used strategy. Their findings revealed that individuals adapted to their cardiac illness by both direct behavioural means and by changing the perceptions of themselves and their illness. While behavioural means involved problem-focused coping aimed at person-environment relationship, changing perceptions required acceptance-focused coping which adopted a more passive acceptance of a situation. In contrast to avoidant-focused and social/emotional coping, both acceptance and problem-focused strategies were shown to be associated with lower levels of anxiety and more positive effect on the individuals at six months. The study concluded that, while problem-focused coping strategies addressed the long term changes, the avoidant, social/emotional and acceptance focused strategies dealt mostly with the short term concerns of the individual.

The previous study is supported by a study by Murberg et al (2004) which reported that avoidance coping strategies resulted in behavioural disengagement and distortion of reality. This was a six year follow up study on a group of 119 clinically stable patients with heart failure who were experiencing reduced physical and social functioning. They found that avoidance coping styles were significantly associated with increased risk of mortality.

Terry (1992), in a three month long study examined the usefulness of a set of stress and coping-related variables to determine the level of psychosocial adaptation among patients who had experienced a myocardial infarction. The sample consisted of 40

individuals, most of whom were males, at two critical times after their myocardial infarction. The first was two to three weeks post myocardial infarction and the second was at three months. The study found that high levels of perceived self-efficacy and access to appropriate resources positively correlated to psychosocial adaptation. The emotion-focused strategies, such as denial and avoidance, were observed to have a tentative value in the early recovery period, but were not found to have had a positive influence in the long term. The use of problem-focused strategies were also not supported in the study, but quality of family relationships, high self-esteem, high internal control beliefs and low anxiety were reported to have had a significant adaptive importance for these individuals.

A number of studies have demonstrated the importance of optimism in psychological and physical functioning of some chronic conditions (Brenner et al 1994; Barnwell and Kavanagh 1997; Carver et al 1993; Kavanagh et al 1993; Taylor et al 1992) and its positive relationship with problem-focused coping strategies and emotional regulation. Fournier et al (2002) investigated the role of optimism in adapting to chronic illness over a twelve month period. It was a quantitative study on 269 patients with diabetes, rheumatoid arthritis and multiple sclerosis. Although improved mental health was reported by patients over the twelve months, stability of positive outcomes and efficacy expectancies were made possible through task-orientated, rather than emotion-orientated coping strategies. Unrealistic positive thinking was shown not to have contributed positively to adaptation over an extended period of time.

Uncertainty during a cardiac illness has been argued to have adverse effects on a patients' recovery, delay in their adaptation and adjustment to the illness (Mishel 1990; 1997). According to Mishel (1997) uncertainty relates to the inability to determine the meaning of an illness, due to its ambiguous and unpredictable nature, complex treatment and care provisions and lack of relevant information. As a result uncertainty has a significant impact on coping strategies for cardiac patients. It is not the total experience in an illness, but uncertainty is a constant occurrence from diagnosis through to living with a long term condition.

Winter (1999) undertook a qualitative study on 22 individuals with heart failure, exploring the phenomenon of uncertainty during an illness. The study concluded that individuals

with heart failure have a tendency to appraise their uncertainty as an inescapable part of life and illness, and that their response to such a situation involves using both emotion and problem focused coping strategies. It claimed that uncertainties about heart failure were, to some degree, influenced by the lack of information and social support as well as the degree and extent of trust on the medical doctor.

Coping has been reported to be an early and ongoing response to personal threat caused by cardiac events. Individuals adopt different coping strategies when faced with their diagnosis. Problem-focused strategies were used to effect change to the situation by direct action for long term stability. Avoidance and acceptance-focused strategies dealt mostly with the short term concerns of individuals. The relationship between uncertainty and various psycho-emotional disturbances was also claimed to be present in cardiac patients. It was suggested that these individuals used the uncertainty experience as an opportunity for positive growth and personal change.

#### **2.4.3 Lived experiences of cardiac events**

A cardiac event can affect every aspect of a person's life and well being. They can impair physical and psychological functioning and cause disruption to individuals' roles and responsibilities (Zambroski 2003; Jackson et al 2000). Most of the studies in this section of the literature review have used qualitative approaches covering a variety of cardiac events such as myocardial infarction, heart failure, cardiac surgery and transplantation.

Adaption to normal life after a cardiac event is a significant element to this study and the choices participants make about accessing cardiac rehabilitation. Doehrmann (1977) conducted an article review on the psychological aspects of recovery from coronary heart disease to explore how individuals adapted their lives following a cardiac event. He concluded that there was a need to revisit the benefits of cardiac rehabilitation for cardiac patients, identify the most appropriate professional bodies for social and psychological counselling, and explore psychosocial effects of the disease on family members. He finally recommended that ways of enhancing the quality of life for people with coronary heart disease needed further work. This is still relevant today as the psychological affects of a diagnosis of coronary heart disease continues to have an impact on a persons' recovery.

Lukkarinen (1999) explored the life experiences of 19 participants following cardiac surgery to see if they adopted an accepting, progressive or non-accepting regressive type of life course. It was a phenomenological study. It was found irrespective of choice of life course that all the participants experienced significant disruption in their lives because of the event. The accepting, progressive course indicated a more optimistic life approach, whilst the non-accepting, regressive course portrayed a less action-orientated and dismissive attitude to the situation. In this latter group individuals showed a tendency to vulnerability, feelings of alienation and loneliness.

Jackson et al (2000) in their study on cardiac recovery and life experiences in 10 women following a myocardial infarction found that earlier reactions of fear, uncertainty and emotional changes were later replaced with more positive outcomes such as return of energy and confidence for the future. By being hopeful of regaining their previous health, or improving well being it provided them with the motivation to fully recover. Supportive networks of these women included partners, friends, general practitioners and other community and religious groups were found to be valuable towards their socio-emotional recovery and adjustment of lives during this difficult time. All the women were married, in a stable relationship and discharged from hospital only three weeks prior to the study.

The life experiences of patients with stable angina were explored in a phenomenological study by MacDermott (2002). The experiences were captured by seven key themes. These were identified as; (1) having to make adjustments to everyday lives imposed by the disease; (2) surprised and shocked by the diagnosis; (3) resigned to the disease being 'incurable'; (4) indignation at the interference of the disease in their lives; (5) being cautious over any physical exertion; (6) reluctantly complying with and living with the medication regime and (7) ignorance of the disease process and the long term outlook. This study showed that participants showed a lack of awareness or information about how to manage their disease, did not know what to expect and why they needed to change their lifestyles. It concluded that cardiac patients needed to develop the necessary skills to manage their lives and condition. By gaining access to information about the cause of the disease, symptoms, actions and side effects of prescribed medication and possible limitations were reported to empower individuals towards modifying unhealthy lifestyle behaviours and improve their well being and quality of life.

Living with a cardiac event has been reported to involve a process that individuals go through towards personal change. Sutherland and Jensen (2000) conducted a qualitative study on a group of 11 elderly women after their myocardial infarction using unstructured interviews to collect the data. They describe the process towards personal change occurring in five phases; (1) searching for a diagnosis; (2) being hit with reality; (3) discovering the nature of the change; (4) adjusting to the change and (5) moving on with the change to re-establish a degree of normality to lives again. Although the phases were progressive, not all the women followed them in sequential order. The authors concluded that readjusting to life after a myocardial infarction involved regaining control, dealing with uncertainties, making sense of the changed situation, seeking independence and sheltering others. This relied on the participants' abilities initially to deal with the physical, cognitive and emotional changes of the event. The study was carried out only eight weeks after the participants' first cardiac event.

Some researchers argue that there is a difference in genders' coping strategies following a cardiac event. Kristofferzon et al (2003) explored gender-role patterns in recovery and adjustment processes to a cardiac event. Women were found to have a tendency to minimise the impact of their disease and did not involve the family in their heart problems. Household responsibilities were found to be important to them and engagement in domestic activities, soon after their cardiac event, have been claimed to aid their recovery. Resumption of paid occupational work and getting fit again were more important to them.

Men's first experience of chest pain and their reactions to it were explored by White and Johnson (2000) in their qualitative study. Although the participants had experienced intense pain, the study revealed that a series of delays to rationalise their symptoms existed before their admission to a coronary care unit. This approach by individuals to make sense of their pain was reported as niggles, doubts and denial of their severity. The authors put forward a Foucauldian perspective based on the concepts of 'gaze' and 'surveillance' as opposed to the Freudian concept of 'rationalisation' and 'denial'. They argued that it provided a better explanation of men's behaviour to ill-health. The notion of 'gaze' and 'surveillance' relates to the order, power and expectations that a social structured system exercises its social agents. Individuals seek to fulfil their own

individual roles, expectations and whole way of living through the process of self-gazing and self-surveillance. The study concluded that men's relationship with their bodies was made more complex and difficult, especially at times of illness. This was because of the mythical archetype of man being built on the ideal of a healthy body form and function to fulfil the expected roles and responsibilities of society. They argued that this type of socialisation has a tendency to lead men away from the knowledge, beliefs and attitudes that would place them in tune with their bodies.

Experiencing a cardiac event involves going through the challenging process of dealing in a positive way with all the reactive psycho-emotional distresses discussed in this section and that of loss and grief. The literature shows the need for individuals to reflect on their previous way of life and health, the ability to overcome perception of vulnerability and the need to be well informed on all aspects of the illness for effective self-management. The importance of making sense of the situation and deciding between a progressive or regressive life-course were important.

#### **2.4.4 Social support**

Appropriate support provisions play a significant role in the readjustment of individuals' lives following an illness, whether chronic or acute. Within cardiac research such provisions have been shown to contribute towards the recovery, rehabilitation and readjustment of individuals, after their cardiac event (Dalal et al 2004; Petrie et al 1996; Bennett 1993). Social support is a multidimensional concept and interactive process. It can be provided by partner, friends, family, work colleagues, health professionals or other people who have had a similar experience. It could take on the form of emotional support, practical assistance, and positive feedback to an individual's importance, capabilities and self worth (Oermann 1991). It can offer a 'cost-effective' approach to promoting recovery from illness (Gottlieb 1991), and coping by individuals who have experienced a cardiac event. Its effect on promoting and restoring cardiac health has been well documented (Con et al 1999), as well as poorer outcomes where that support is not found (Con et al 1991).

Cardiac rehabilitation uses social support to inform, guide and motivate individuals to become self-dependent again by restoring or rebuilding the persons' self-confidence, self-esteem and psychosocial functioning. Social support is aimed at sustaining long-

term functioning and stability, and it is a two way interactive process between the individual and the personnel providing the support. Boutin-Foster (2005) argued that previous research into social support has focused on emotional support and less on instrumental support in relation to health behaviour modification. They conducted a qualitative study on 62 patients with coronary heart disease to evaluate the types of instrumental social support perceived as being the most helpful to health behaviour modification. They found that instrumental support provided by social networks allowed individuals to engage more easily in healthy behaviours, alleviate stressful situations and facilitate the process of receiving medical care. They found that social support, through social networks, was a valuable resource that could motivate health behaviour modification.

The impact of peer support or self help groups to enable an individual to gain better health, have been explored. They are voluntary, patient-orientated groups, with a variety of services to assist individuals with long term conditions deal with their adaptive problems (Gussow 1976). Despite a growth in the development of these groups nationally few studies have examined such groups (Hildingh and Fridlund 2004). Colella and King (2004) looked at the impact of peer support groups to cardiac recovery, with particular relevance to patients who had undergone cardiac surgery. It focused on the impact of a group on patients shortly after their surgery and provided limited insight into the longer term impact on the individual patient.

A randomised control trial involving 67 men evaluated an interventional peer support by linking former patients who had recovered from cardiac surgery with those who were about to undergo a similar operation (Parent and Fortin 2000). The control and intervention groups both received standard information about surgery and recovery from the health professionals, the intervention group received additional support. They were visited three times 24 hours before surgery, on the fifth post operative day and then week four after. The effectiveness of this interventional peer support was measured by its impact on anxiety, self-efficacy expectation and self-reported activity. The study showed no significant differences between the two groups on self-efficacy expectations and self reported activities at four and eight weeks post surgery. A significant decrease in anxiety level was reported for the interventional group prior to surgery. Peer support was found to be very useful by patients in the intervention group.

The support experiences of individuals with coronary heart disease and their next of kin, who belonged to a self-help group, was explored by Hildingh et al (1995). This was a phenomenological study with a sample of 10, using unstructured interviews to gather the data. The study revealed the establishment of an 'open and unrestrained climate' within the self-help group was vital to allow for support to be meaningful and purposeful for both recipients and providers. Through mutual feelings of caring and belonging, empathic understanding, solidarity and friendship, such a climate was found to promote equality among the members, a sense of well-being and confident coping abilities. It was also observed that social support worked positively for extrovert individuals, who took the opportunity to make full use of the 'caring relationship' provided by the group. Although the self-help group made an important contribution in overcoming shared struggle, it provided a descriptive account of the experiences of mainly elderly individuals. Further qualitative work on the long term contribution of self- help groups is needed, particularly on different age groups.

Fleury's (1993) naturalistic study revealed the existence of two main ways that social networks were perceived to initiate and maintain health behaviour in cardiac patients. They were named as 'enabling' or 'limiting' and found to influence the individuals' reinstatement of self-worth and self-determination after their cardiac event. Although such networks involved building and sustaining relationships in an unconditional and stable environment over time, such networks were found to be either 'enabling' to some or 'limiting' to others. The participants experienced no difficulties when support was provided by people known to them, others found the support received from people not known to them as challenging and stress inducing. The participants in the study experienced support through social networks on average for ten weeks as part of their outpatient cardiac rehabilitation programme.

This section has highlighted the extent to which social support networks have contributed to the recovery of cardiac patients. Most of the research on the value and importance of support provisions focused on the short-term impact on patients' recovery. The future potential of self help groups requires further exploration to assess the extent to which individuals' long term adjustment needs and well being can be met.



#### **2.4.5 Patient involvement in decision making**

Recent health policy in England has demanded greater involvement of patients and the public in the commissioning of health and social care services. It is seen as a way of improving service quality, reducing health inequalities and giving good value for money for the commissioners (Martin 2009). But paternalism has been endemic in the NHS, with the assumption over the years that doctors know best. Decisions have been made on patients' behalf without involving them in their care or service provision (Coulter 1999). The underlying ethical principles of patient autonomy underpin the development of public and patient involvement legislation and strategies. The three objectives of patient and public involvement are: Strengthened accountability to local communities, a health service that genuinely responds to patients and carers, and a sense of ownership and trust (Strengthening Accountability: Involving patients and the public 2001). The Health and Social Act (2001), section 11 gave the NHS plan a legislative power. The document calls for a partnership between health providers, patients and the public to be at the centre of modernising the National Health Service.

The concept of patient participation has become part of nursing practice and it is now widely used as part of the vocabulary of professional nurses. According to Clayton (1988) it enhances decision making, dignity and quality of life by empowering people to take control of their own health needs. Batehup (1987) agrees that participation enables patients and their families to manage health problems more effectively. For patients with heart disease it is important to encourage them to take control of their health and be part of developing services for the future. Nurses are required to actively encourage patient participation as part of their every day care, but the lack of clarity associated with it has led the concept to become a nursing rhetoric or even a cliché (Cahill 1999). Health professionals have differing views of participation or involvement. Legislative documentation has not been clear about what constitutes participation and how it should be consistent across the NHS.

The involvement of patients in their care, service provision and evaluation has implication on the professional power of the nurse in her/his caring role. Foucault (1980) viewed power as inseparable from knowledge. Nurses gain this knowledge through training and experience to which patients are not privy. According to Brownlea (1987) without appropriate information and knowledge patient participation is tokenism. Clear

guidelines need to be available for nurses to enable them to involve patients and the public in service development or improvement. Evaluating or auditing services needs skills that may have training requirements that need to be highlighted at appraisals or professional reviews, and the cost implications from this need to be met by the organisation. Professional nurses may have their own agenda for promoting patient participation (Clayton 1988) and it may limit the power of participation or lead to the extension of power by the nurse, leaving the patient frustrated and dissatisfied, or vice versa, if by giving up a degree of power or control for patient participation, the nurse feels de-skilled.

Patient participation can have a positive impact on nurses' roles in promoting involvement in decision making and partnership working. Berg (1983) suggests that with greater patient participation the nurses' roles of empowerment and facilitator are being illuminated rather than lost. Benner (1984) sees nursing expertise as a source of power that has a transformative influence on patients' lives. This power is based on respect for and connection with others, rather than exerting power over patients, it enables power that enhances personal control. Chinn (1995) characterises power by valuing the personal power of each individual, all of whom have a role to play in decision making and choice. Arnsten (1969, p.216) argues "participation without redistribution of power is an empty and frustrating process for the powerless.

Historically there has been much rhetoric about patient and public involvement, choice in service development and provision from all political aspects. It has gained momentum over recent years as people have become more assertive of their health needs, spurred on by Government campaigns and the media. According to Section 11 of the Health and Social Care Act (2001) NHS organisations are already required by law to consult on service planning, development and decisions that affect the operational levels of delivery. Expecting the general public to have strong views on service development and operations within the NHS makes several assumptions. It assumes people are interested in this aspect of their health service, not accounting for those who want to be well or those who do not access services that are available to them. It suggests "more effort needs to be made to involve the harder-to-reach groups that may be affected by the proposed change or more information needs to be given" (Section 11, P.2). Involving hard- to -reach patients in practice development has to be balanced with the tensions

this highlights about choice. A patient should be given the opportunity to access services, and get involved in its implementation, but needs to have a choice on whether to participate or not.

The NHS plan and the Health and Social Care Act wanted to provide patients and users with a voice in the consultation process for service development, but remained unintentionally discriminatory for those who do not access services, and therefore do not get involved in service development. More recently the National Institute for Health and Clinical Excellence (NICE, 2008), have supported previous government legislation to give patients and the public a greater voice in healthcare provision. The patient and public involvement documentation have set out plans for a change in social action i.e. involving people in their health care choices and consultation on the services they want, but in the future more is needed to develop these social actions further.

Patient and public involvement overall is a useful tool in the development, progression and redesign of health care services, but more work is needed to involve representatives from hard to reach groups, and more power needs to be devolved to patients and the public. Involving patients who do not access services in the development, planning and initiation of new services would improve the quality, access and relevance of services for all users. Further research is needed to examine why patients do not access services and involve them in decision making and control of their illnesses.

## **2.5 Summary**

From the literature review it has become evident that there are a number of gaps in knowledge on a number of issues. There has been quantitative research into cardiac rehabilitation and socio-economic factors that provide an effective base for this study. Cardiac rehabilitation has been well documented as a cost effective way to help cardiac patients to adjust to their cardiac event and modify health behaviours in the long term. Despite this, the review showed that very little qualitative research had been undertaken into exploring why patients from lower socio-economic backgrounds do not access these services. Allowing individuals from lower socio-economic backgrounds to describe their experiences, beliefs and perceptions will expand the current thinking about cardiac rehabilitation for those who provide these services.

The review looked at the psycho-emotional and psycho-social aspects of research into cardiac patients and how this may impact on their decision making and health choices. It has given a broad overview of current published research available and the need for further study from an in-depth, interpretive perspective. This would add to our knowledge of why patients do not access services, leading to recommendations that could improve the patients' journey. The next chapter provides the theoretical framework that has informed this study.

## CHAPTER 3 – THEORETICAL FRAMEWORK

### **3.1 Introduction**

In the previous chapter there was an exploration of the literature review that underpins this research. This chapter will discuss why a qualitative, phenomenological approach was chosen to support and progress previous research. Initially the study was going to use an action research framework, but early on in the process it became apparent that further in-depth exploration was needed into the feelings and beliefs of participants before such a process would be beneficial. Improving services as a practitioner required knowledge of the issues involved in patients' decision-making about declining a phase three cardiac rehabilitation programme. Theoretical framework possibilities were explored prior to commencement of the study to establish the most effective approach to highlight the experiences of the participants throughout their health journey. A Heideggerian phenomenological approach was chosen as the philosophical paradigm for the study.

### **3.2 Qualitative research and the development of a theoretical framework**

Before undergoing the study process, and from the literature review undertaken in chapter two, a decision was required as to whether to further investigate the research question from a quantitative perspective, which had largely been done, or to explore the question from a qualitative angle, where little was already published. At a broad level research can be characterised as either a positivist or naturalist paradigm. Positivism or quantitative research involves the systematic collection of numerical data under conditions of control using statistical procedures for analysis. Naturalist or qualitative research focuses on the holistic aspects of individual experiences, using subjective analysis (Polit and Hungler 1991). The latter approach was chosen, enabling an exploration of participants' experiences.

Unlike quantitative research, with its focus on causal relationships described in terms of observation statements, verification and prediction, qualitative research explores human behaviour and actions (Porter 1996). The researcher observes and records events and relationships through text, dialogue, participant observation, photography and video. Once analysed, data may be used to describe participants' thoughts or relationships, to

clarify a specific human experience or to improve understanding of complex phenomena (Porter 1996).

Porter (1996) said that qualitative research is founded on four levels of understanding; (1) ontological is what is the nature of reality; (2) epistemological is the exploration of what counts as knowledge of the real world; (3) methodological explores how the understanding of the nature of reality might be gained and leads to (4) method, where techniques are used to collect evidence about what exists. The most appropriate methods are those which allow the researcher to become involved in the participants world, allowing the participant to freely describe the meanings and motives that are the basis for their actions and interactions.

The lack of qualitative research into access to phase three cardiac rehabilitation programmes by lower socio-economic groups was the basis for choosing this for the study. Within sociology, anthropology, psychology and philosophy a qualitative approach may be adopted if it supports the research question. Different disciplines approach qualitative research in different ways. Social anthropology, for example has a long association with ethnography, emphasizing the importance of the researcher's immersion in the data through fieldwork and observation. Nursing has a closer association with grounded theory, interpretative phenomenology or action research (Beck 1992, Streubert and Carpenter 1995).

For the purpose of the study, the researcher chose the approach most relevant to support the research question. Some approaches have aspects in common. Action research lends itself to community and service development, whilst grounded theory, interpretative phenomenology and ethnography are all exploratory (Sarantakos 1993). A summary of these approaches and their suitability for this study will be examined in the next section.

### **3.2.1 Action research**

Prior to the refinement of the research question action research was considered as a theoretical framework, as it is a qualitative approach with strong links to community development and participatory involvement. It is a process of observation, description,

planning, acting, reflecting, evaluating and modifying that can involve patients at all levels (McNiff 2002).

Waterman (2001) defined action research as 'a period of inquiry that describes, interprets and explains social situations while executing a change intervention aimed at improvement and involvement. It is problem focused, context specific and future-orientated. Zuber-Sherritt and Perry (2002) argue that action research is more suitable than traditional research for improving practice, professional and organizational learning. They see two types of action research projects, core and thesis. The core action research project involves the researcher within a workgroup of practitioners from their organisation whilst the thesis action research project involves the research in a 'workgroup', supported by fellow students and supervisors supporting the requirements for their qualification, with doctorate level progressing through two cycles of the process.

The core action research is only a third of the process, with the thesis action research taking much more time, reflection and theoretical underpinning. According to Carr and Kemmis (1986, p7) only emancipatory action research is real action research, "...having strategic action as its subject matter; proceeding through the spiral of planning, acting, observing and reflecting; involving the participation and collaboration in all phases of the research activity".

According to David (2002) there are some problems relating to participation in action research. Involving patients in research as partners or collaborators becomes a form of "advocacy" (p.11), raising the question of ownership in the study. He argues that action research "seeks to be democratic and opposes a professional expert model" (p.12), so avoiding a top-down model of research, policy formation and implementation. Although the study was influenced by the participants, ownership of the study was with the researcher, and any service developments or changes would need to be negotiated at an organisational level through management structures and operational plans. Any changes within service development must be realistic, time specific and manageable within existing budgets.

In order to enable action research to make an impact on service development and provision, an established understanding of the feelings and beliefs of participants

needed to be in place. The cyclic approach of this theory can only be continuous if established research exists to support its use. The study's theoretical framework was revisited to explore the most relevant approach that could, in the future, make an action research study more tangible. There were a number of other approaches that could be adopted and these are explored further within this section of the thesis.

### **3.2.2. Ethnography**

Ethnography has been described as both theory generating (Agar 1997) and a holistic approach to developing a theoretical framework (Polit and Hungler 1997). It has made a major contribution to the development of the human sciences over the last twenty years (Lowenbourg 1993). It emphasises the natural environment of the research participants and the relationship between research participants and the cultural world (Spradley 1980).

An ethnographical study requires extensive periods of time 'within the field' and total immersion in the research participants' way of life. Immersion through participant observation enables the researcher to become the 'instrument' of research (Clifford 1997), and in a prime position to acquire knowledge of the values and beliefs of the participant.

There is tension within the ethnographical approach between "naturalism and reflexivity" (Denscombe 1998, p.73), with some ethnographic researchers arguing for a stand alone, unchallenged description of the subjects world, others proposing a generalised view of human society. This generalisation builds the researcher's own values and beliefs into the research process, whilst clarifying their role within the study's development and outcomes. Hammersley and Atkinson (1995) argue for a reflexive approach to ethnography, saying that overt or covert participation in others' lives must lead to personal interpretation of social phenomena.

An ethnographic study collects data through observation, interaction or interviewing (Fetterman 1989). It is analysed by the ethnographer looking for regularity in the organisation of topics under study, moving back and forward between situations and the practical worlds of the participants (Benner 1994).



It would have been inappropriate to use ethnography for this study because rather than exploring the routine daily lives of people whom had undergone a cardiac event, this study was concerned with their experiences following an exceptional, life changing event. The study was not concerned about the day to day activity of the participants, but a specific event, that is their cardiac event.

### **3.2.3 Grounded theory**

Grounded theory is an approach used to explore social processes that are present within human interactions (Streubert and Carpenter 1995). Grounded theory is an important research method for the study of nursing phenomena. It explores the richness and diversity of human experiences through field research in natural settings such as hospitals, clinics or nursing homes. It uses systematic techniques and procedures of analysis that enables the researcher to develop a theory that provides significance, theory-observation compatibility, generalisability, reproducibility, precision rigor and verification (Strauss and Corbin 1990).

Glaser and Strauss (1967) first described grounded theory which over the years has been refined and developed. Stern (1980) outlined the importance of grounded theory in nursing research and its importance as a rigorous research method. She describes five steps in the grounded theory process as (1) collection of empirical data; (2) concept formation; (3) concept development; (4) concept modification and integration and (5) production of the research report.

Since the work of Strauss and Glaser different competing schools of grounded theory have developed. Glaser has an inductivist approach (1992, 2002) whilst Strauss, first alone (1987) and then with Corbin (1990, 1998) allowed for more use of deduction. From an inductive perspective, theory emerges from specific observations and generated data. The deductive perspective allows for the researcher to develop specific predictions from general principles.

The main purpose for using the grounded theory approach is to explore social processes within the goal of developing theory. It needs a research question that identifies the phenomena to be explored in depth, and an assumption that all of the concepts

pertaining to a given phenomenon have not been identified. It requires the research question to be refined as data generated and analysed in the study.

In a grounded theory approach data continues to be collected until saturation is achieved. Data can be collected from interviews, observation, documents or a combination of these sources (Stern 1980; Charmaz 2002). The role of the researcher in grounded theory emphasises that research is conducted in a naturalistic setting; the researcher has to openly recognise they have a role in the investigation (Stern et al 1982) as they examine the data, code, categorise, conceptualise and write down their thoughts throughout the process.

The research question for this study was clear in its objectives, and a grounded theory approach would have not benefitted the study as the development of theory that can be tested and retested was not required. The theory development could not proceed without first understanding the experiences and feelings of the participants in a broad view. By using a phenomenological approach the researcher and participants were able to explore and describe health journeys. The study was not designed to be tested and retested but to inform practice and service development for the future.

Action research, ethnography and grounded theory are all philosophical approaches to research methods that could be used for a study into why people from lower socio-economic backgrounds do not access cardiac rehabilitation programmes in the future. The need first is for a basic understanding of the experiences, feelings and perceptions of the participants to provide a framework for future work in the area. Phenomenology allows freedom for the participants to provide rich, in-depth insights into their health journey.

### ***3.3 Rationale for phenomenology***

Historically phenomenology has undergone four stages of development, (1) realistic phenomenology; (2) constitutive phenomenology; (3) existential phenomenology and (4) hermeneutical phenomenology associated with the works of Heidegger, Gadamer and Ricoeur (Cohen 1987). Merleau-Ponty (1962) defined phenomena as a solid structure that existed in the intimate relationship between the objects and the subject. He suggested that there was not one single definition of phenomenology but that it should

be recognised and practised as a mode of thinking towards a fuller philosophical consciousness.

Heidegger was a student of Husserl's but gradually developed his own phenomenological approach. According to Darbyshire (1994) the distinction between Heidegger and Husserl was that the Husserlian question of 'what does it mean to know?' was fundamentally adapted by Heidegger to pose the question 'what does it mean to be?'

Hermeneutic phenomenology is the study, explication and interpretation of the persons' lived experiences, emphasising an honest and in-depth examination of phenomena. It allows participants the freedom to explore their own perceptions through semi-structured interviews. As this study explores the experiences of individuals who have experienced a cardiac event, and their decision not to attend a phase three cardiac rehabilitation programme phenomenology provides a theoretical framework that can provide the in-depth examination of the participants' experiences, using a Heideggerian approach.

Heidegger (1962) argues that for an individual to understand their world around them they need to understand 'Being'. We must overcome the problem of being as it is the first stage in the true understanding for the world around us. In order for participants to contribute to this study, their understanding of being is fundamental to the research and the analysis of the findings. This will be developed and described within this chapter.

### ***3.4 Heidegger's philosophical thinking***

The Heideggerian approach to this study allows the research to focus on the participants' views of their health journey and the reasons for their decision to refuse phase three cardiac rehabilitation programmes. According to Heidegger the fundamental condition of all existence is the discovery of the 'Being' of all beings. His preoccupation with the question of 'Being' had originated from his dissatisfaction with the development and progress of Western philosophy. He argued:

".... Not only that the question of the meaning of Being is one that has not been attended to and one that has been inadequately formulated, but that it has become quite forgotten in spite of all our interest in metaphysics" (Heidegger 1962, p.43).

Heidegger describes his approach to phenomenology as hermeneutic. Hermeneutic is a Greek term, 'hermeneia', meaning to express, interpret and to translate. According to Walters (1995), hermeneutic inquiry entails exploring the meanings of every day life. The hermeneutic-phenomenological philosophy directly challenges the notion of meanings, derived through the mental representations of phenomena independent of the reality of a situation. It has the dual property of being a theory and method for interpreting human action. It is seen as a process that people use to make sense of their everyday world "within a cultural background, involving language, personal and bodily practices" (Walters 1995, p.798).

In 'Being and Time' (Heidegger 1962), Heidegger argues that individuals have an understanding of their existence and of what being is. It is developing understanding based on their experiences of encountering phenomena. He believed that his approach to the study of 'Being' has a significant role in establishing a more primordial understanding of the existential nature of all entities in the world. It is necessary to clarify the terms 'being' and 'Being' that Heidegger uses in his approach. A 'being' with a small 'b' refers to any particular entity that exists in the world such as humans, animals or inanimate objects. 'Being' with a capital 'B' represents an analytical interpretation of beings in their contextual frameworks (Watts 2001).

Heidegger has had a significant influence on other philosophers and thinkers, such as Sartre, Merleau-Ponty, Gadamer, Foucault and Derrida. His influence reaches across humanities, social sciences, theologies and since the mid 20<sup>th</sup> century, nursing. It has provided nurse researchers with a much needed alternative approach to studying nursing issues (Benner 1994; Plager 1994; Gullickson 1993; Walters 1995; Kenny 1994). It has much to offer in terms of recognising the fundamentals of individualism and the uniqueness of human beings (Jasper 1994; Benner 1984).

Many of Heidegger's critical ideas were developed from his contemporaries and predecessors, insulating him from the criticism of being directly influenced by any one particular philosopher or school (Inwood 1997). Being and Time (Heidegger 1962) was his response to the earlier work of Husserl, the father of phenomenology, his teacher and mentor. Heidegger was further influenced by the work of other philosophers such as Kierkegaard and Nietzsche. Kierkegaard highlighted the enigmatic nature of the human

situation, which required commitment by individuals towards a search for a meaningful and valid way of life (Perkins 2000). Nietzsche (1968), on the other hand, supported the notions of 'will to power' and 'self-assertion'. He urged individuals to exercise their free will and oppose conformity to established morals and practice, as they were meaningless to everyday life. Heidegger was influenced by this thinking, about ideas on the possibilities of life and authentic living. This has relevance to this study into people from lower socio-economic backgrounds and their decision making. The participants in this study chose not to attend phase three cardiac rehabilitation services after their cardiac event, negotiating the benefits and costs to their everyday lives, and a belief that to conform would not help them to overcome their illness.

The study focuses on the participants experiences from their cardiac event, and how they coped with this either alone or with the support of others. Heidegger argued there is an inextricable link between individuals and their world (Walters 1995). Heidegger argued that it was impossible to explain 'things' as products of consciousness when they were detached from their everyday functioning in the world. He believed that it was only possible to understand 'Being' of what it is, so long as it is done through an ontological approach of study. He emphasised that people, as beings, are naturally and inevitably related to, and are part of the world. This hermeneutical phenomenological approach allows for an interpretive philosophical stance that listens to experiences, allows participants to express their thoughts and the researcher to interpret these. The researcher, through their knowledge and experience as a nurse could compare and contrast the participants' first hand accounts about life after a cardiac event. The researcher's values and beliefs in her world had to be recognised within the research process, with judgement of participants' thoughts put aside.

Using a Heideggerian approach allows the study to explore the participants view of what has happened to them as they see it, their truth. It requires the researcher to be experienced in this area of study, and able to understand their views in a non-judgemental way. Heidegger's phenomenology argues that everything is interpretable, but this interpretation is tentative and not the final and absolute answer to the truth. Truth emerges from the interaction of the individual with their world; it is alive and happening all the time. He suggests that for any interpretation to occur there must be prior understanding of the experiences of the interpreter. This is only possible once 'Being',

inclusive of human being and other existential beings, has been totally understood in its totality in a particular world.

Dasein is the focal point of Heidegger's inquiry and he finds the most necessary component of Dasein as Being-in-the-world. It translates from the German as there-being, an entity exclusively belonging to human being. It is chosen by Heidegger as the basis for his theory because he feels it is the only way in which we are to discover what it means to be, its characteristics also help this study, primarily because it has within itself a mode of self relation and for this reason must be considered ontical. This ontical ability to relate to our own being within the world is what produces our there-being.

Being-in-the-world can be split into three separate constitutive factors which Heidegger refers to as in-the-world, Being-in and the entity. The concept in-the-world is a state we find ourselves in with no choice. Being-in represents all beings in the same place have the same being. Finally the entity itself is the understanding of the world and the experiences within it.

Fundamental to the Heideggerian approach is the need for existence. The participants in the study wanted to find meaning after their cardiac event, to re-establish their existence and find a way to come to terms with their cardiac event. This is related to their Being-in-the-world position. They had pre-determined ways of relating and engaging with the cardiac event, known as 'the established self'. They had to develop through their 'threatened self' where the cardiac event was seen as a de-stabilising and disruptive life-threatening situation 'towards the adjusted self' where they could make life changes to re-energise and re-assert themselves. Such notions represent the direct need for an analysis of our actions in the world because such notions also represent a direct effect of Being-in-the-world.

The Heideggerian approach allows the study to understand and focus on the participants' subjective experiences, and the way they chose their path through the journey. The study does not concentrate on the event itself, but the adaption of the individual to the experience. This enables a better understanding of what a person feels and how they cope with the diagnosis. It also helps researchers and service providers to

understand the choices individuals make and the reasons behind them deciding not to access health services.

The Heideggerian approach focuses on being, ourselves, rather than external entities. The relationship between knowledge and the world is also an issue that requires depth in its analysis. Being able to exist and experience in this world requires an individual to have knowledge of this world in order to be able to achieve being-in-the-world; the ability to come to terms and cope with the event that has occurred, based on self-reflection. This self-reflection is crucial for the researcher and the participants to help find a common meaning for what has happened to them.

### ***3.5 The Phenomenological research process***

Hermeneutic phenomenology, as advocated by Heidegger is about in-depth personal descriptions of the ways events and experiences are perceived. It emphasises the ordinary language that participants use and its relationship to daily life, and participants are encouraged to respond openly and freely through their interviews. This integrates with this study, participants felt at ease to talk freely about their experiences and feelings in an informal setting.

Sense is made of participants' experiences through interpretation of what is said. According to Reed (1996), phenomenology, as a method of research, provides access to the real life experiences of individuals in a way that preserves their integrity and context. The challenge faced by researchers is that they can never fully understand the true, inner experiences of their research participants (Reinharz 1984). Heidegger suggests this can be made possible by being part of the same world, both ontically (factually) and ontologically (nature of Being), in all its constitutive entities. Although he provided some direction about how to complete a phenomenological enquiry, researchers still need a workable model when implementing such a project.

The absence of a concrete research framework has proved to be a real challenge to many researchers. Oiler (1982) highlighted some fundamental phenomenological rules and beliefs about the 'nature and existence' of particular phenomena. He argued that by addressing the 'reality', 'subjectivity' and 'truth' components of the phenomenological study, researchers would be better prepared. He emphasised the importance of

spontaneity when collecting data about an individual's lived experiences. According to Banomis (1989), this approach directly impacts on preserving the uniqueness of the experience and allows for understanding of the descriptive data at the analysis phase of the research. It is further argued that because of the uniqueness of findings generated by this research, it is possible to make generalisations (Field and Morse 1995; Beck 1992; Colazzi 1978).

As a subjective study the reality of the participants' experiences is spoken from their own perspective, with their own rationalisation of the truth of what happened to them. The researcher may have a different experience of what the true health journey had been, but this must be disregarded, as it is the participants' thoughts that prevail. Although the researcher's knowledge and experience should be recognised as important for the process to be implemented effectively, their personal views may influence the outcome so must be dealt with. Being aware of these concerns and reflecting on the research question throughout the process can be enough to allow the phenomenological approach to be effective.

Koch (1994) argues that researchers adopting a hermeneutical-phenomenological approach to nursing research should be aware of the philosophical underpinnings and the appropriate methodologies for data collection and analysis. This should include trustworthiness, rigour and the value of the researchers to participate at all stages of the research inquiry. Whilst the Heideggerian approach promotes an ongoing conversation with the participant and the researcher, there are not clearly identified methods for achieving the phenomenological inquiry. Annells (1996) and Paley (1998) suggest the procedural steps for research can be implemented once the central concepts of the approach have been interpreted and internalised appropriately by the researcher.

Interpretation occurs through the appropriation of understanding, which itself is made possible in the presence of three pre-understandings (Heidegger 1962). These are identified as fore-having (something we have in advance), fore-sight (something we see in advance) and fore-conception (something we grasp in advance). The development of understanding can only be made possible through interpretation. Through appropriation, interpretation takes understanding to a higher level of projective possibilities.



In the study, the barriers that existed for participants accessing phase three cardiac rehabilitation were explored within the whole patient journey from the cardiac event, to diagnosis and the aftercare they received. In order to understand the issues raised it is necessary to revisit the concept of 'Beingness'. By doing so both nurses and researchers can compare and use the study's findings to develop a greater insight into previous and future studies into the phenomena. The value of interpretative methodologies is based on the fact that the provision of care is a situated, dynamic and inter-subjective phenomenon (Benner 1984; Koch 1999).

According to Heidegger ontological understanding aims to generate a deeper understanding of the issues that contributes to what is already available and familiar to us in our every day life. The next section will explore the value of phenomenology to nursing research.

### ***3.6 The value of phenomenology to nursing research***

During the late 20<sup>th</sup> century there has been an increase in phenomenological research in nursing as it provides a descriptive, as well as an interpretive understanding of phenomena (Benner 1994; Koch 1999; Draucker 1999). The benefits to nursing research are described within this study and provide the basis for choosing phenomenology for this study in understanding the experiences, feelings and beliefs of participants who chose to decline phase three cardiac rehabilitation programmes as part of their recovery.

Nursing researchers find phenomenological approaches to nursing sciences relevant and useful (Oiler 1982; Benner and Wrubel 1989; Holmes 1996; Taylor 1994; Drew 1993; Koch 1995; Annells 1996; Porter 1998). Phenomenological approaches to nursing research has been criticised as being restrictive because of its inability to go beyond interpretation (Lather 1991; Rose 1993). Van der Zalm and Bergum (2000) suggest that, although phenomenology does not seek to develop a predictive and prescriptive theory, it does influence a thoughtful, reflective research process. They argue it is about borrowing other people's experiences and their personal reflections, fulfilling a meaningful understanding of those experiences in the context of human existence.

According to Spiegelberg (1982), phenomenology should not be seen as an undifferentiated philosophical school of thinking, but as a movement. There has been

some misunderstanding over the use and application of phenomenology and nursing research. For the purpose of this study the focus is on a Heideggerian approach of philosophical thinking to avoid misunderstanding and to avoid methodological slurring (Crotty 1996; Paley 1998).

Heidegger's work has been refined over the years in relation to nursing phenomenology. Reeder (1985) argues that a Heideggerian approach has benefits to nursing research as it encourages the skill of listening to the participants' experiences. By listening to what is said, in the context of their experiences it allows lived experiences to be seen to contribute to an understanding of what they feel through the language they use. It allows researchers to highlight nursing questions that could have an impact on service development, giving a voice to those participants who have previously not been consulted in a qualitative approach. Examining the issues participants raise can achieve an understanding of experience and possibly improve these.

### ***3.7 Theoretical framework decisions***

Based on Heidegger's key philosophical concepts of phenomenology a number of underpinning assumptions are used as a broad foundation for the theoretical framework of this study. These are (1) human beings are social and self-interpretive beings; (2) truth is in the interaction of the individual with their world; (3) interpretation involves the interpreter and the interpreted in a dialogical relationship; (4) Meaning is maintained through the disclosure of Dasein (Heidegger 1962) and (5) being in the world. The participants were encouraged in an informal way to express their feelings and experiences through the interview process in a social and self-interpretative way. They gave their accounts in a perceptive way that was their subjective truth within the dialogue with the researcher. This gave the study a view of how the participants saw their world through their health journey from diagnosis, 'the threatened self' to the re-assertion of their lives, 'towards the adjusted self'.

These concepts have manifested in the planning and implementation of this study. The study wants to explore the participants' experiences through their own stories, their own self-interpretation of what has happened to them. Their stories are their narrative of what has happened to them through their health journey and how it has affected them.

According to Heidegger everything is interpretable as long as it involves the interpreter and the interpreted in a dialogical relationship. The participants involved in this study and the researcher establish a relationship to enable their beliefs to be expressed. The participants show their being in their world through their dialogue and experience.

### **3.8 Summary**

This chapter has discussed phenomenology as a valid, qualitative approach to research. It has explored some of the alternative qualitative approaches that could have been used for the study, ethnography, grounded theory and action research, giving the argument for the approach chosen, the Heideggerian approach to phenomenology, and the appropriateness of this philosophy to this study. It has given the framework for the data analysis of the study. Phenomenology allows the participants in this study to tell their story subjectively, based on their truth and meaning of events following their cardiac diagnosis, and be interpreted so that practice development can improve in the future. Phenomenology has a valid place in nursing research in exploring the meanings of an experience, interpreting these meanings and informing practice. In the next chapter the theoretical framework will be put into the context of the research design and method.

## **CHAPTER 4 – RESEARCH DESIGN AND METHODS**

### ***4.1 Introduction***

This chapter defines the research design and methods used for the study within the theoretical framework of the previous chapter. It describes how the methods used support the phenomenological approach in the context of ethics, sampling, data collection and data analysis. In order to study patient's perspectives and beliefs a qualitative approach was agreed on at an early stage in the process. Positivist scientific approaches were rejected as the study was exploring subjective views that could not be generalised in a quantitative manner.

Semi structured interviews were used for data collection in order to obtain rich, in-depth descriptions of the patients' experiences following their cardiac event. Interviews have advantages over other methods in that they bring out the lived experiences of participants in their own words, describing their own feelings. Interviews also encourage the researcher and the participants to develop a close relationship based around the conversational element of the approach. By choosing to interview cardiac patients the researcher hoped to collect anecdotes, examples and stories to gain an insight into the participants' world of living with a cardiac event, and the reasons for their choosing not to attend phase three of cardiac rehabilitation. This relates to the research question and the aims of the study.

### ***4.2 Rationale for the research design***

For this study the researcher had an interest in developing services for people with cardiac disease and their families. The well documented concern that services were not accessed by those from a lower socio-economic background has been described in previous chapters. Previously, patients who access services are asked about their experiences through questionnaires and evaluation forms, with services being developed from these to improve the patient journey. It became apparent when designing services that those who did not access them were not asked for their opinions or input in providing relevant care for the whole community. A project steering group was developed to assist the process and to give the opportunity for the researcher to discuss

transcripts and findings. It was a task group that lasted until the interview process was complete. This will be further explored later in this chapter.

Phase three cardiac rehabilitation programmes tend to be short term, delivered at venues some distance from an individuals' home and structured to suit the majority, not each persons' need (Dracup 1985; Cooper et al 1999). Repeated hospital admissions and frequent telephone queries from concerned patients and their relatives highlight the issue. Post diagnosis, patients struggle to re-organise their lives and come to terms with what has happened to them (Wyer et al 2001). The literature search highlighted a lack of knowledge into the reasons why people from lower socio-economic backgrounds access services.

All the issues above influenced the development of the study and became the basis for the design and chosen methodology. The theoretical framework discussed in the previous chapter also enabled the researcher to assess the most appropriate approach to a qualitative study that would highlight the feelings and experiences of the participants. Ethical approval was sought from the University school ethics department and the local NHS ethics group.

### **4.3 Ethical issues**

When undertaking any research it is important for the researcher to consider the ethical issues that may arise and to recognise the relevance of values for both the participants and the researcher in order to develop an ethical framework. The main principles for health care ethics as described by Edge and Groves (1994), that are relevant to this study are, (1) respect for autonomy, asserting the right of individuals to participate in and make decisions about and for themselves; (2) beneficence, which is the duty of health professionals to seek the good for people in their care under all circumstances; (3) non-maleficence, the duty to avoid or prevent harm to the individuals and (4) justice, a fair distribution of outcomes. These principles were transferred from health care to health research to provide a basis for safe and effective research for the purpose of this study.

The values and beliefs of both the participant and the researcher in the study were addressed. According to Brechin et al (2000, p118), "Values are a set of beliefs, ideas and assumptions that both individuals and groups hold about themselves and the society

they live in". Each person holds their own personal set of values, as well as values shared with different social groups such as work, leisure or religion. Sometimes one value can conflict with another value creating dissonance. This can lead to a sense of disharmony, sometimes compromising personal beliefs. Before undertaking a research study it is important to understand that different values exist and for researchers not to impose their beliefs upon the participants.

Judd et al (1991) outlined the need to weigh up the potential risks and benefits of working with research participants. Risks include physically or emotionally harmful consequences resulting from the research process. All due care was made to inform the participants in the study of the nature of the research and what was expected of them, making every effort not to mislead them.

Interviews require probing questions to enable the researcher to obtain quality, in-depth, rich data. Quinn-Patton (1990) said that probing interviews should not necessarily be seen as a harmful experience, but as an opportunity for participants to share their stories with a stranger, using their time to vent their anger or discuss their feelings or work through issues and emotions. The researcher needs to be aware of risk and be able to work through any ethical dilemmas raised by the study.

The participants needed protecting within the study to assure confidentiality and informed consent. It was essential to safeguard the rights of each individual participating in the study, allowing them to have the right to self-determination (Streubert and Carpenter 1995). This means that they have a right to be informed about the study, providing an informed choice. Voluntary consent requires a description of the study including the possible risks and benefits of participating. May (1979) draws attention to the problems of informed consent in relation to nurses, and the multiple roles they have within the research and clinical contexts. At the first meeting of the researcher and the participant it is made clear that the researcher's role will not influence their personal care throughout their health journey.

The confidentiality of participants was assured through the informed consent procedures and secure storing of the data. Beaucamp et al (1982) argued that participants who are involved in interviews risk the public exposure of their comments through report writing

and other publications. To protect the study participants, the researcher made every effort to preserve participants' anonymity, making sure that data was treated as confidential information. Participants were pre-warned that the interview would be recorded, but if they refused, a hand written record of the interview would have needed to be made (Fetterman 1982). The participants were given a contact address and number for queries. Participants were advised that if they wished to withdraw from the research they could do so at any point, with no effect on their usual nursing care.

Provision was made by the researcher for participants who were unable to read, had sensory deprivation or did not speak English to be offered relevant assistance. An interpreter was made available by the researcher's organization for those who require this service. As well as operating within ethical frameworks, the researcher was sensitive to legal requirements. These include the Human Rights Acts (1998 and 2000); Data Protection Act (1998) and the Access to Health Records Act (1990). The researcher was also working within the UKCC Code of Professional Conduct. Data was locked in a cabinet, only accessible to the researcher.

Though the broad guidelines stated above bring to the attention of the researcher some of the ethical dilemmas faced during the course of a study, it is up to the researcher to uphold their own set of values and principles (Wall 1995). The researcher tried to make decisions that were not an attempt to harm or influence the participants in any way, ensuring the conduct of the study was facilitated to the highest standards. Information was obtained in a productive way avoiding exposure to serious risks of negative consequences.

#### ***4.4 The 'validity' or 'trustworthiness' of data***

Lincoln and Guba (1985) argued that the issue of trustworthiness was simple, the researcher needs to persuade the audience that the study findings are worthy of notice. They claimed three activities, (1) prolonged engagement; (2) persistent observation and (3) triangulation as increasing the probability of achieving credible study findings. Prolonged engagement allows the researcher to build up trust with the participant, together with persistent observation that is both intense and focused. Denzin (1978) broke triangulation into four modes, (1) multiple sources; (2) methods; (3) investigators

and (4) theories. Together they improve the likelihood that interpretation will be acceptable, through the support they provide to each facet of data collection.

Silverman (1993) warned against trying to triangulate different accounts, believing that if triangulation is used it should be done sparingly and not at all stages of data collection. He argued that using data to adjudicate between accounts, forces the researcher to undercut one account with another, ignoring the context and character of social interaction. For the purpose of this study, triangulation was not applied but the researcher was aware of its possible influence on data and data analysis. The participants' recollection of their cardiac events was personal to them and expressed freely. By triangulation some of the richness and personal feelings would have been diluted or possibly lost. The researcher felt that taking each account as a singular experience brought meaning to the analysis process.

Hammersley (1992) questioned the view that qualitative data is easier to validate than quantitative data. He was concerned that the researcher may become complacent by claiming that empathy, experience and involvement with the participant group is a reliable basis for validating data. He also disclaimed the assumption that only the researcher can be the judge of the study's validity, having the greatest insight into the study. He recommended a mixture of insider and outsider involvement to validate findings. This is supported by Quinn-Patton (1990) who agreed that a second party should be involved. Hammersley (1992) argued the second party should be from the participant cohort. This study involved a project steering group in its infancy to support this, made up of healthcare professionals and patients.

It is necessary to explore the issues in validating data (Reason 1981). Reason described three, (1) description; (2) intentional interaction and (3) meaning. Description examines whether the researcher is able to discriminate and map what they are experiencing in the study. Intentional interaction looks at whether the researcher is observing the outcome of intentional changes made by the participants in the way they conduct their lives. Validity of meaning, understanding or interpretation of phenomena is concerned with reaching beyond description towards explanation. The above views, though differing in many aspects, have one thing in common. Data can only be validated or seen to be trustworthy when a combination of issues are considered. These include the activity of research, the cognitive process of validation and the involvement of external measures,



with second opinions and the participants' own perceptions to add weight to the approach taken by the researcher.

#### **4.5 The Sample**

In order to address the research question effectively the sample was chosen to reflect the lower socio-economic group under scrutiny. A copy of the electoral wards was obtained from the Borough council and a summary of the five poorest wards were identified (Fleming et al 2005). This provided the researcher with the locality of the sample group. Health professionals within secondary and primary care were informed of the need to recruit participants from the five poorest electoral wards who had refused phase three cardiac rehabilitation. They were asked to introduce the research study to the patients and ask if they were willing to participate. The patients were then approached by the researcher where a full verbal explanation was given of the study, with written information provided with the consent form. The sample recruitment was perceived by the researcher as a potential threat to the study, as patients who did not access services may not agree to participate in research. In practice this part of the research process was effective and no barriers existed. This will be further explored within this chapter.

There are various forms of sampling that a researcher can adopt, so a comparison of these and the rationale for choosing purposive sampling will be explained. Sampling in qualitative research identifies participants that have the characteristics or live in circumstances that are relevant to the study (Higginbottom 2004). The most common types of sampling in qualitative research are convenience, purposive, theoretical and selective.

Convenience sampling involves individuals being easily accessible. Purposive sampling includes participants who have specific characteristics or features. Theoretical sampling, mostly used in grounded theory allows for new or emerging phenomenon to be explored during the study. Selective sampling is the selection of cases prior to the start of the research process. As the research is trying to describe and interpret the participants' experiences, convenience sampling was not deemed relevant. Sampling, based solely on convenience, is not consistent with the phenomenological goal of

exploring the diversity of individual's experiences within the common experience (Porter 1998).

Purposive sampling was chosen for this study with participants purposely selected to represent cardiac patients who lived in a lower socio-economic area. This form of sampling aims to establish the typicality of the settings or groups (Murphy et al 1998) and select participants according to the criteria outlined in the research question. It relies on small numbers of participants with the aim of studying depth and detail (Miles and Huberman 1994). Phenomenological studies expect the participants' experiences to be described in depth and with detail rather than it forming a generalization for the population as a whole.

The criteria for selection was any patient with a diagnosis of coronary heart disease, referred from secondary care, that lived within the five most deprived electoral wards in Darlington, who had not attended a cardiac rehabilitation programme. The study included anyone with angina, myocardial infarction, heart failure, undergone revascularisation or a cardiac surgical procedure. Patients were excluded if they did not have the mental capacity to give informed consent, or patients with severe breathing problems, and therefore unable to commit to an interview. There was no discrimination of age for the sample.

Participants were accessed from current case loads within the community cardiac team. None of the participants were from the researcher's caseload to prevent clinician bias, and ensure the participants viewed the researcher in the research role, rather than the clinical role. All the patients had been referred from the local district hospital or tertiary centre so it was necessary to discuss the research study with relevant health care professionals from these areas so they were aware of the study. A letter was written to each GP within the eleven GP practices to inform them of the study and ask for any concerns or objections to be sent. All the GPs agreed to the research and were interested in updates on its progress. Participants of all ages may have other health conditions that prevent them from attending a conventional rehabilitation programme and they were not excluded from the research process, as they can be offered home based programmes.

The participants were approached by health professionals within secondary and primary care. Those participants had refused to participate in phase three cardiac rehabilitation programmes and lived within the five poorest electoral wards of Darlington. The researcher initially met with thirteen patients individually to offer them the opportunity to participate in the study, with three declining. Those who declined did not give a reason. The ten patients were interviewed at home or at a place of their choice. There were eight men and two women. The age range was from 34-85 years old. They had all been offered and refused phase three cardiac rehabilitation within the three months prior to the researcher approaching them.

Participants who worked were seen after work at a time to suit them. An initial meeting was set up with the patient to explain the research and address any issues. As the researcher was an insider researcher, the participants were given a clear summary of the researcher role in this study. Any nursing issues raised at this meeting were dealt with so that the interview could take place without outstanding problems. The researcher did not wear uniform for the interview, whereas when she visited patients she was expected to do so. The patients were given a patient information leaflet outlining the research (See Appendix B). The patients were left with a consent form to sign and return using a stamped addressed envelope (See Appendix C).

Initial interview questions were developed that would complement the study (See Appendix D). The interviews were recorded using a digital recorder. Initially thirteen patients were approached, and ten agreed to participate by returning their stamped addressed envelope. At the start of the research process it was hoped to interview or use focus groups to explore the carer perspective but this was not successful for a number of reasons; (1) the patient did not have a carer or in some cases next of kin; (2) patients did not want their families involved in the research; (3) patient's relatives felt it was nothing to do with them; (4) other reasons such as work, family commitments. All the participants lived within the five lowest socio-economic electoral wards in Darlington. Of the sample seven were married or living with a partner and three lived alone, three were in full time employment and seven did not work either due to incapacity or retirement.

The study was supported before and during the interview process by the development of a project steering group. The group consisted of a consultant cardiologist, a GP, a secondary care rehabilitation nurse, three people from the coronary support group and three people who had been offered rehabilitation but declined. The group was chaired by the researcher. It helped to produce the main areas of concern and a direction for the study, whilst acting as a critical support for the researcher.

The members of the project steering group were chosen for their experience and knowledge, whether from a professional or lay person perspective. The patients on the group were able to contribute their thoughts without feeling threatened by the professionals, the researcher providing clear ground rules about the use of professional jargon and careful facilitation of each meeting. Each meeting lasted an hour bi-monthly.

The use of a project steering group in a phenomenological study is unusual but was justified by the rich, in-depth perspective the group brought to the data collection. The group did not influence the researcher's analysis, but provided areas of concern that could be explored from their own experiences. It provided further vigor to a study that was developed and implemented by a researcher embedded in the subject area. After the first five interviews the group was disbanded as its role had been completed and succeeded to provide a framework for the interview direction and progression. The members of the group have been kept informed of the research findings and the development of the thesis through one-to-one discussion and meetings at the local support group.

#### ***4.6 The Interview***

The literature review showed there were different methods that could be used to collect and analyse data in nursing research. An appropriate method has to be used to suit the research question to be addressed. Interviews and questionnaires have been the most popular tools for collecting data in the previous published studies. In this study, semi-structured interviews were the method chosen to support the phenomenological approach to the study.

Having considered the ethical implications of interviewing, this section focuses on interview style and approach. Structured, semi-structured and open-ended interviews

would have been effective for this study. The researcher needed to assess what form the interview would take to bring out the best from the participants. The interview could be face to face or telephone. It was decided to facilitate face to face interviews to enable the participants to feel at ease and for the researcher to be able to see the participants' reaction to questions. The interview involved a verbal communication between the researcher and the participant during which information was provided to the researcher (Burns and Grove 1995). Interviewing is a flexible technique that has a higher response rate than questionnaires and includes participants who would otherwise not be able to take part in research such as those whom are unable to read.

A structured interview is strictly organized so that the interviewer asks every participant the same question in the same order (Burnard and Morrison 1994). A strict and detailed interview schedule is drawn up listing a set of pre-defined question. Structured interviews leave no room for deviation with all the questions within the schedule must be asked. Extending a topic is discouraged and the format is rigid and repetitive. Questions may be asked by a variety of interviewers and answers can be easily organized and sorted for analysis.

Telephone interviews have a high response rate with a direct and fast access to participants, with no limits to length. The researcher can correct misunderstandings and motivate the participants. They are useful if the research needs a population that is not geographically concentrated, or is not close to the researcher (Judd et al 1991). They do have some disadvantages too. Not all participants will have access to a telephone. Questions that need a visual aid must be re-worded and some questions are awkward to ask over the phone. Telephone interviews cannot rely on visual cues, so the body language of the participant cannot be explored (Judd et al 1990). The main disadvantage of telephone interviews is that confidentiality may be an issue. It is not always convenient for the participant to speak openly and freely about sensitive issues at the time when the researcher calls and it may be difficult to find time during the day to talk free of interruptions.

Unstructured interviews flow freely and rely on a spontaneous generation of questions in the interaction. Researchers must be able to think quickly, employing skill and ingenuity in carefully drawing out participants' experiences, whilst at the same time recognizing

any ambiguous responses (Sudman and Bradburn 1982). By nature an informal event, the open-ended interview usually takes place within the participants' own environment, enabling the researcher to collect a large number of conversations, perhaps using the same participant more than once.

The researcher is not obliged to use an interview guide or pre-defined questions, and data collection may vary dramatically from participant to participant (Quinn-Patton 1987). The open-ended questions in an unstructured interview reveal a rich source of unexpected information and, if the researcher is skilled enough, they can encourage participants to go into great detail. For this method to work effectively the researcher should present questions in such a way that participants do not feel obliged to respond in a particular way, except within the terms of the question (Atkinson 1971). However, because there is no thread running through them, other than the initial concept, analysis is more complex.

Interviews are a form of self-reporting and it must be assumed that the information given is accurate. Subject bias is an issue with interviewing and the validity of the findings, as is inconsistency in data collection from one participant to another. Different opinions exist about how phenomenological interviews should be facilitated. Some claim that one initial question is sufficient (Halletts 1995), whilst others suggest that there must be some structure to the interview process (Britten 1997; Charmaz 1994).

Semi-structured interviews were chosen for this study as the data collection method, being less rigid than structured interviews. Basic questions formed a matrix on which responses could be given. The questions can be probed and explored more fully depending on the participant response, but guide the participants through their journey without the constraints of a structured interview. Semi-structured interviews give the possibility of rich, complex data that is effective for exploring questions, understanding processes and generating potential explanatory models (Bernard and Ryan 2010). The interview questions allowed the participants in this study up to an hour to explain their thoughts, beliefs and feelings.

Although semi-structured interviews can be undertaken over the phone or web, for the purpose of this study face to face interviews was chosen. This is because it was possible

to clarify questions as the interview proceeded. Establishing a relationship of trust with the participant was essential in order for them to feel comfortable talking about their experiences (Streubert and Carpenter 1999). This was achieved by adopting an informal interaction and allowing the participant time to answer questions and discuss issues, as if in a normal conversation. Prior to conducting the interviews a few broad areas were identified as useful to the study. These were established by a project steering group who met monthly prior to the study and during the interview process. There were 5 main areas included in the questions, (1) cardiac experiences since diagnosis; (2) personal beliefs about health; (3) social support; (4) barriers that existed to participating in cardiac rehabilitation and (5) other issues the participant wanted to discuss.

The interview length ranged from 30-60 minutes long, all at the participants' homes at their request. The participants spoke freely during their interviews about their experiences, answering all questions. Initial questions about the participants' non-attendance at phase three cardiac rehabilitation programmes highlighted misunderstandings and misconceptions of what the programme entailed and the benefit to their well-being. The other questions did not pose any problem for the participants and they talked freely and frankly about what had happened to them since their cardiac event. Only one interview was conducted in the presence of a friend, partner or carer. The participants were assured verbally and in their written information sheet that their data was confidential, and their names would not be shared with anyone else. They were advised that all personal tapes and transcripts would be destroyed at the end of the research process.

#### **4.7 Case Examples**

Following the interviews the data was collected and analysed. The analysis is discussed in the next section. The researcher incorporated case examples in the process so that a sample of the participants could give their complete story. According to Bernard and Ryan (2010), exploring individual cases are a means of getting an in-depth understanding of something – a program, an event, a place, a person or an organisation. They can be regarded as the “end product of field-orientated research” (Wolcott 1992; p.36), and as a way to develop “general theoretical statements about regularities in social structure and process” (Becker 1968, p.233).

Other literature describes the use of case studies, rather than case examples and this can be linked to the case examples within this study. Merriam (1998) distinguishes among ethnographical case studies, focusing on the culture of a group; sociological case studies, focusing on social interactions; historical case studies, which examine how institutions or organisations change over time; and psychological case studies, which examine the inner workings of peoples thoughts and emotions.

Life histories are case studies of people, what happened to them and how they felt as they went through various experiences and stages. Most are focused on particular topics such as a person's work history, migration history, and sexual history or in the case of this research, a person's health journey. According to Guba and Lincoln (1981; p.377) it is important not to over-generalise case study data or let them "masquerade as a whole" when they are "but a part, a slice of life".

According to Burns and Grove (1995) case studies are a good source of descriptive information that can be used as evidence to support theories. For the case study design the participant's history and previous behaviour patterns will be explored in detail in relation to the research problem. The context and setting of the study will be described, their interactions and how these influence the study.

The value of case studies literature to the case examples within this study is that it illuminates new ideas, and allows the researcher to tell each participant's story in depth, allowing the reader to appreciate their experiences. Using case examples allows the researcher to use a blend of approaches from case study literature to express the participants' journey. These range from the historic case study approach to psychological and social case study approaches.

#### **4.8 Alternative Data Collection**

As discussed, semi-structured interviews were chosen by the researcher to explore the participants' experiences. This supports the research question and provides the study with some rich insight into the participants' health journey in relation to their decision not to attend a phase three cardiac rehabilitation programme. In this section a brief outline of alternative data collection techniques will be explored and the reasons for deeming them inappropriate explained.



Koch (1998) promoted the use of diaries and journals as sources of lived experiences. They are an effective approach if the participant is reflecting on one event rather than a journey through life changing events. Like Koch, Van Manen (1990) encouraged self-discovery through diary writing. Diaries are useful for recording insights into the research process. Diaries require the participant to have the ability to express themselves in writing or on video. Video diaries would require equipment, a requirement for participants to be able to use it and the confidence to talk into a camera. Audio diaries could have been considered but again would have required recording equipment of a good quality.

Observational approaches could have been used for the data collection, similar to those adopted by Cornwell (1984). Observational approaches encourage the researcher to become committed to an in-depth exploration of the phenomena at hand. It allows data to be collected by means of observing and recording behaviours or activities of interest (Polit and Hungler 1991). In any observational setting whether it be in a laboratory or in the participants' natural environment the researcher cannot possibly be present at every event. Observational research methodology was not chosen as the study was not examining the here and now, but the participants' journey from cardiac event to the time of data collection.

Interviews provided the researcher with immediate, personal descriptions of the participants' health journey and decision making that did not require certain educational levels, expensive equipment or an invasion of their everyday life. Van Manen (1990) describes the hermeneutic phenomenological interview as a vehicle for gathering rich, in-depth narrative. It is important to recognize that phenomenological description as only an example (Van Manen 1989) allowing the researcher to explore the deeper significance or meaning of the lived experiences explored.

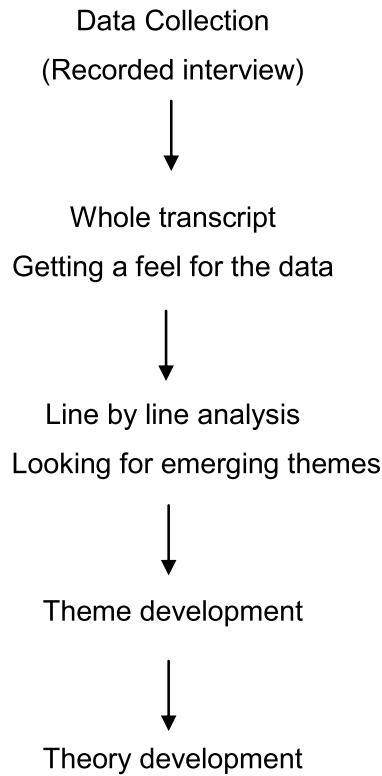
#### **4.9 Data Analysis**

After a review of the literature on methods of analysing interview data thematic analysis was chosen as a means to explore the experiences of the participants using a phenomenological approach. An example of the process can be seen in Fig 3.

Thematic analysis is a means of analysing lived experience descriptions, though some descriptions may prove to be a richer source of information than others. Themes enable

the researcher to capture “the phenomenon one tries to understand” (Van Manen 1990 p.87), by allowing the researcher to simplify and focus on description. Once themes have been discovered, the researcher must consider how best to put thematic notions into the thesis. Van Manen’s thematic analysis technique covers three different approaches to revealing the phenomena, (1) the wholistic or sententious approach; (2) the selective or highlighting approach and the (3) detailed or line-by-line approach. The wholistic approach enables the researcher to look for a single phrase that sums up the essence of the whole text. The selective approach is a means of capturing the main, vital statements or phrases that are representative themes of the experience. The line-by-line approach calls for an examination of each sentence to see what is revealed about the experience being described. For the purpose of this study the last approach, the line-by-line approach was used following an overview of the whole transcript. From this, themes emerged and theories could be developed from the findings.

**Fig 3 Analytic approach used for the study**



Phenomenology uses personal stories as a window into the experiences of the narrators (or participants) to try and understand their experience. The object of the study is the experience of the participant, and not just the story itself (Bernard and Ryan 2010). The interviews gave the participants the opportunity to tell their health stories which became the data for the research (Coffey and Atkinson 1996). For the data analysis to be effective within a phenomenological study the data needs to retell the story in such a way that it is understandable to the reader. They are personal accounts of peoples' motives, experiences and actions and the meaning we get from them. They are not a single statement or phrase but a lengthy account with reflections from the researcher (Holloway and Freshwater 2007).

Clandinin and Connelly (2000) argued that experience is the starting point and core of qualitative research. People, time, actions and events are embedded in the stories that individuals share with each other. Kleinman (1988) describes stories told by people about their illness or perceived health. He argues that health professionals can learn about suffering and vulnerability by studying the illness experiences of their patients. The stories show how a patient makes sense of their situation and illness. They also show how a patient perceives they have been treated, and how they adapt to challenges to cope with their condition. This is a relevant concept with this study as patients were asked about their illness journey, their beliefs of what happened to them, and how they were treated.

The researcher asked the same initial open-ended questions of each participant to allow them to talk freely, and then used probe questions to explore issues further and then analysed the data for common themes (Zakrzewski and Hector 2004), or as Sayer (1984) says 'relations of similarity'. Selecting quotes from participants required empathy on the part of the researcher, with personal biases removed where possible. Writing quotes into the study that depict particular themes provides the reader with the story of the participants' experiences in a summarised form.

According to Holstein and Gubrium (1995) the analytic objective of the interviews undertaken are not merely to describe the data but to show how and what is being said relates to the experiences and lives being studied. The data cannot speak for itself, but rather the researcher needs to establish and document the meaning-making process by deconstructing what is said to show the reader the hows and whats of the participants' stories.

The data was explored using coding techniques to establish common themes and any deviant themes that emerge. The data was collected and coded by the researcher to enable the feel of the rich data to be experienced first hand. This was done by a line by line study of each part of the data text and writing emerging themes. Care in coding the data had to be taken to ensure the excerpts documented were in context with the theme it had been placed in. According to Roe and Webb (1999) a code is a means by which individual items of data are defined and indexed on the interview transcript. For the purpose of this study a line by line scrutiny of ten transcripts of semi-structured

interviews was undertaken. Then, across the whole body of the transcripts, every identifiable significant statement or comment was assigned a number, using the paragraph and line number to assist in identification of themes. If a statement fitted into more than one category they were placed in the one that fitted most in the context of the study. Software packages exist for this process, but each transcript was examined manually to enable the researcher to get a feel of the transcript content. A grid was developed based on Sirur (1997) to show how often particular themes emerged across the ten interviews and within the individual interviews too (Box 1, chapter five). The researcher then numbered the times each participant mentioned the theme in the transcripts to give a flavour of the data and also give direction for further analysis. Silverman (1993) thought simple counting of themes was of value, as the researcher found in the initial stages of analysis. But for a phenomenological approach this is not enough and more in-depth exploration of the data is required.

The participants' stories were told by the researcher through quotes from the transcripts under the headings of emerging themes. Selecting quotes that make it clear how a person really experiences something is challenging to the researcher, requiring empathic understanding of the phenomenon being studied (Bernard and Ryan 2010). According to Wiltshire (1995) it is important to think about the terms 'story' and 'narrative' to see if there are some distinctions between them, not take them for granted and understand they are interchangeable. The participants in the interviews gave a story through conversation with the researcher about their experiences. After looking at the transcripts a number of themes from the data were highlighted. After this it was decided to put the stories back together in the form of case examples to view the whole picture of three of the participants to allow the flow and richness of the data to be understood more deeply.

The case examples were an opportunity for participants' whole story to be transcribed to support the themes that had emerged. The data analysis gave the researcher emerging themes through the interviews, whilst the case examples brought the data back together to provide an in-depth account of the participants' experiences and personal recollections. This will be described further in chapter five.

#### **4.10 Summary**

This chapter has provided the reader with a comprehensive analysis of the methods used to facilitate the study, and the reasoning behind the choices made. Following an overview of ethical considerations, the chapter concentrated on interviewing techniques, sampling methods and sample size, before discussing the data analysis. The next chapter will explore the findings from the study and link these into the phenomenological perspective.

## **CHAPTER 5- Findings One**

### **5.1 Introduction**

The previous chapter described the research design and methods used for the study using a Heideggerian approach to data collection and analysis. The findings are separated into two chapters. In this chapter findings are presented thematically so as to be consistent with the data analysis. The thematic presentation provides a systematic elaboration of all the essential emergent themes within the data. It describes the cardiac events of participants and their feelings and beliefs at the various stages of their health journey from diagnosis to recovery, incorporating phases one and two of the cardiac rehabilitation process, which they received. The reasons for non-attendance at phase three of the rehabilitation programme are explored as the participants enter the fourth phase of their recovery. The second chapter will collate the experiences of three of the participants into case examples, bringing the data back together to show the rich, in-depth exploration of their experiences. This breaking up and restoring of data into the complete form provides the reader with a snapshot of the lived experiences of the participants. It shows the study from a health promotion perspective, exploring the decisions the participants made and how they negotiated lifestyle changes where appropriate for their personal journey towards the 'adjusted self'.

According to Heidegger (1962) it is important to understand the forces that may have predetermined or influenced the way the participants reacted in their everyday life. This chapter will explore the feelings, beliefs and perceptions of the participants through the themes that have emerged from the study through the interview process, and three case studies will be presented. This enables the data to be taken apart for analysis and also examined as a whole. Following a synopsis of the themes the findings will conclude with the three emergent elements of phenomenology that best describe the participants' health journeys following their cardiac event, (1) the established self, (2) the threatened self and (3) working towards the adjusted self. These elements encompass the participants' health journeys from their diagnosis to the time of data collection.

## 5.2 The Themes

Following an overall feel for the data by transcribing and reading the transcripts, a line by line data analysis of the transcripts was carried out by the researcher. There were eleven themes that emerged and were coded (Box 1). Each theme will be discussed, with reference to the words of the participants. By choosing interviews as the method for data collection the researcher was able to ask participants to talk freely about their health journey and how this related to their decision to refuse a phase three cardiac rehabilitation programme. It provided data that articulated the participants' feelings about their experiences.

Box 1. Emerging themes from data collection (Adapted from Sirur 1997).

<b>Emerging themes</b>
1. Cardiac event stories
2. Sense of symptoms
3. Perceptions of what has happened to them
4. Cardiac rehabilitation inhibitors
5. Quality of life
6. Fear and shock of diagnosis
7. Choices and risks
8. Support – informal and formal
9. Change drivers
10. Fear of hospitals
11. Time and Financial restraints

### 5.2.1 Cardiac event stories

All ten participants discussed their cardiac events. Eight participants had been diagnosed with a myocardial infarction, one with angina and one participant had undergone cardiac surgery. Of the participants, one person who had a heart attack, had previously had cardiac surgery for angina, and the person who had undergone surgery had previously been diagnosed with congestive heart failure. At first glance cardiac incidents may not be regarded as a theme, merely as a fact, but it was important to keep it as a theme as it contributes to the stories that emerge from the transcripts.

All the eight participants who had a myocardial infarction explained it in lay terms as a “heart attack”. Using lay terms as health professionals involved in delivering cardiac rehabilitation is important as it ensures provision of information at the education level of



the patient, avoiding medicalised terminology. The participants all presented with similar symptoms of chest pain, nausea, vomiting, feeling clammy and breathless. Two of the participants experienced indigestion type symptoms and took indigestion remedies, but without success. Participant one (Page 1, line 10) *"I was in pain all Thursday night, I didn't sleep. I took gaviscon, I thought it was indigestion"*.

Participant three (Page 1, line 20) *"I just palmed it off as indigestion"*.

All the participants who had experienced a myocardial infarction went to hospital. One participant delayed going to hospital until the following day, going to his GPs after a night of chest pain (Participant One), one was taken from the bingo to hospital by car (Participant five) and the other six participants who had a myocardial infarction went by ambulance as an emergency (Participants two, three, four, seven, eight and ten), although participant ten delayed for an hour.

Participant ten argued with a friend about when to call for help, he said *"...I think I am going to have a heart attack and he says your're joking me and I said no and he went out and got me a quarter pounder with cheese and fries (laughs) but anyway 10 o'clock come and this pain oh bloody hell and he says why don't you call the ambulance and I says bugger off theres nothing wrong with us man..."*. He eventually called the ambulance at 10.25pm.

The participant with angina (Participant six) presented to his GP with chest pain and was referred to the hospital where he underwent blood tests and a Bruce protocol treadmill test where it was diagnosed. He said *"I went to me own doctors first who sent me to hospital, had the treadmill examination such as everything else, blood pressure, cholesterol and they found I had angina"* (Page 1, line 9).

The participant with congestive cardiac failure woke up one morning coughing bloody, frothy sputum and his partner rushed him into hospital (participant nine). He spent a total of eight weeks in hospital, both at the local district hospital and then the tertiary centre where he underwent a mitral valve repair and coronary artery bypass grafts.

The role of family, friends, health professionals, members of the public and research participants in how they sought help differed between the participants and where they

were when the cardiac event occurred. One participant was at work when he had his myocardial (participant seven) and his colleagues called the ambulance. One woman at the bingo had the ambulance called by a first aider at the venue (participant three), the other waiting for her partner to come and drive her in the car (participant five). The family of participants two, eight and nine called the ambulance. Participant one went to the hospital from the GP practice after the GP called the ambulance. Participants two and ten were taken to hospital in an ambulance called by friends. Participant four called the ambulance himself, knowing he was experiencing a myocardial infarction from a previous cardiac event. Participant six did not go to hospital by ambulance. After visiting his GP he was given an out-patient appointment to attend a chest pain clinic the following week and prescribed anti-angina medications.

The cardiac event stories set the scene for further themes that have emerged from the transcripts. They show the participants' 'established self' and pre-determined ideas of relating and engaging with their cardiac event. Their views on the cardiac event were influenced by what they previously knew about cardiac disease, and the symptoms they experienced.

### **5.2.2 Sense of Symptoms**

Within the participants there were different levels of self management and acceptance of symptoms and what these signified. Participants found their own balance between symptom control and quality of life, making decisions as to whether to actively treat them or ignore them. This was influenced by their previous cardiac experience and their awareness of the potential life threatening consequence of the event.

Apart from participant two, all the participants described their sense of symptoms in-depth. Sense of symptoms was briefly touched on in the cardiac event stories, but here we explore this theme in more depth. Participant six discussed his angina management at length. He said he was experiencing less angina pain since making lifestyle changes, and commencing the cardiac medication. He said he only used the anti-anginal spray (Glyceryl trinitrate sublingual pump (GTN)) periodically.

Participant six (Page 3, lines 28-34) *"I say I probably use it every week at some stage. It depends what I'm doing. I had a bit of a squirt last night down at the allotment but just a*

*small spray not a full spray*". When asked if he takes it before he does something he continues (Page 4, lines 1-3) *"Well not normally but before I go on the bike I usually have one before I set off but as I've said before the only thing that puts me off is it normally gives me a headache and that's the only thing that stops me using it more"*. Headaches are a well known side effect of this medication (British National Formulary, March 2010), yet for the benefit of reducing his angina symptoms he continued to take it effectively, and manage his symptoms well.

Participant nine, with the support of his partner was aware that he was unwell when he complained of *"bubbling a bit"* (Page 1, line 3). Later in the interview he describes how he experienced atrial fibrillation at home (Page 2, line14), recognising it from an episode in hospital which corrected itself without any treatment or further episodes.

The sense of symptoms in the participants who had experienced a myocardial infarction showed differing coping strategies for their symptoms. Participant one had drunk a full bottle of Gaviscon before he would accept the symptoms were not indigestion. He went to see his GP the following day and was referred to the hospital the following week but would not stay in. He argued *" They said I had a heart attack and the next 48 hours were crucial but I said its too late for that, I had been at work since it happened so I discharged myself"* (Page 1, lines 15-17).

Participant two did not describe any sense of symptoms in the transcript. When asked what he had felt like he said *"I just had a heart attack and it just come on."* (Page 1, line 2). Throughout the interview he made no mention of his feelings about the actual myocardial infarction.

Participant three explained clearly her symptoms throughout her journey. She said *"Yes I was at the bingo but I'd been like that for a few months I'd been getting this pain. It all started about Christmas and I'd been really fighting for breath all the time even just walking down the street uhmm, uhmm (shows gasping movements) to get me breath and it must have been this straining that I'd been like that since Christmas until July and I wasn't any better but since I had the heart attack its gone back to normal"* (Page 1, lines 4-9). She says she did not discuss it with her GP, as she felt it was either her asthma or indigestion. When she had her myocardial infarction she describes how she felt *"lousy*

*and the sweat was pelting off us it was"* (Page 1, line 24). She also describes how she sometimes experienced palpitations.

Participant four describes his symptoms as *"I got pains in me chest, it crippled me and me friend phoned for the ambulance and I ended up in hospital"* (Page 1, lines 3-5). He knew he was having a myocardial infarction, and understood the seriousness of the situation. During his cardiac event he remained calm and listened to the advice of his friend.

Participant five had her myocardial infarction at the bingo. She describes her symptoms as *"My arms just felt so heavy. I just couldn't lift my arms so I thought what the dickens is going on this isn't something to do with the arthritis, it's a completely different sort of pain, I've never had anything like this before..."* (Page 1, lines 13-15). She then describes how the pain then goes to her chest and she phones her partner to pick her up and take her to hospital. She refused the bingo staffs' suggestion that they should call an ambulance as she wanted her partner with her. She was frightened and concerned about what was happening to her.

Participant seven experienced his myocardial infarction at work. He describes his symptoms as *"I had severe chest pain while I was doing a training course. I was in a pipe and thought it was claustrophobia so I got meself out with the help of a fella. When I got outside I felt the pain worse and I felt sick and clammy"* (Page 1, line 4). He was taken to hospital by ambulance. A first aider at the scene advised him he was probably having a heart attack. Fellow employers were worried that he looked grey, was clammy and showed classic heart attack symptoms. They reassured him and supported him until the ambulance arrived.

Participant eight was nervous during the interview and so his answers were concise and short. His symptoms were described as *"chest pain"* (Page 1, line 4). He understood what was happening and able to realise he needed to get into hospital despite the need to leave his wife who was terminally ill. His son reassured him and stayed with his mother when the ambulance came. He was taken to hospital by ambulance and stayed on coronary care for a few days.

Participant ten tried to ignore his symptoms all day. Eventually he called the ambulance after eating a quarter pounder burger with cheese, and some persuasion by his friends. His first symptoms of the day are described as *“I had these chest pains that were really really bad but I had been having chest pain for about two months”* (Page 1, line 6). Later in the transcript he describes how he manages his angina pains with his GTN spray. He has difficulty in targeting his mouth and needed a couple of sprays to manage to control the pain. He experienced angina whilst doing minimal tasks around his flat. Throughout the day he knew his symptoms were likely to be a cardiac event but did not want to go into hospital.

All the participants gave a clear account of their journey at the beginning of their diagnosis, with all those who mentioned sense of symptoms mentioning it close to the start of the interview. Their stories support the ‘established self’ element that was emerging from the data but also begins to highlight the ‘threatened self’ element. The imposition of the cardiac event, through the ‘threatened self’ becomes de-stabilising and disruptive life-threatening situation for the participants.

### **5.2.3 Perceptions of what has happened to them**

The perception of the cardiac event was an important issue for participants in how they coped with the event. All but participant eight discussed their perceptions of what was happening to them as they experienced their cardiac event. Some perceived the symptoms as indigestion whilst others had a very clear idea of what was happening. Their ways of dealing with their diagnosis varied from accepting it, to discharging themselves from hospital.

Participant one thought he was experiencing indigestion but was compelled to seek medical advice once he realised the gaviscon would not alleviate the pain. Even after diagnosis of a myocardial infarction he said *“I prefer to ignore it and get on with it”* (Page 2, line 16). Participant two did not discuss his myocardial infarction symptoms but was aware of the tests he had and why they were performed. He describes having a treadmill test with the consultant cardiologist and then going home, only to be readmitted with a further cardiac event, which he recognised as *“another one came on”* (Page 2, line 7). He was readmitted four times.

Participant three also perceived the myocardial infarction as indigestion initially but realised quickly that it was more serious. She describes how in the ambulance the paramedics *"wired me up onto the thing (Electrocardiograph) and they was giving me them injections what stop the clotting so they said it was a heart attack and that's all I can remember"* (Page 1, lines 32-34). Despite understanding her diagnosis she discharged herself from hospital two days after her myocardial infarction claiming that *"I'm not one of them that likes to brew over things, I just get on with things. I always have"* (Page 2, lines 14-15).

Participant four, despite eating a heavy meal knew he was having a myocardial infarction and knew he needed to call an ambulance immediately. In hospital the realisation of what had happened, he said *"As much as I can remember they gave us morphine and that took the pain away and ummm they were putting needles into me and talking to me and that was about it until the next morning and I realised what was happening and what had happened umm and they gave us tablets to take and things, but were very good though"* (Page 1, lines 15-19).

Participant five knew straight away what was happening to her as she had lived with long term health conditions for years. She had diabetes and arthritis, so when her heart attack came on she phoned her partner to come and get her. When asked by the first aiders at the bingo if it was her diabetes she calmly said *"I think we'll go one better tonight lasses."* (Page 1, line 22). Following discharging herself from hospital and a night of severe pain, only marginally relieved by morphine she saw her GP the following day. He took blood samples and rang her up later to say she had definitely had a heart attack. She understood the diagnosis and had a clear perception of what it meant to her at the time and for the future. She described the symptoms as *"the heavy arms are one of the many, many side effects. Some people may think they've got indigestion or some people have higher pains or very low addominormal (abdominal) pain"* (Page 2, lines 8-11).

Participant six understood all the tests he had to diagnose angina. He underwent a treadmill test, had bloods taken for cholesterol and his blood pressure measured. He was prescribed cardiac medication that he understood, and knew why he was given them. Participant seven, following his heart attack at work was rushed straight to hospital

and to theatre where he had a stent inserted immediately. By the time his wife arrived at the hospital he was in a ward and was able to tell her what had happened to him. He said *"When I got to the hospital they did an ECG and rushed me straight to a theatre where I had a stent put in"* (Page 1, lines 7-8). Despite the speed of his journey from work to hospital and theatre he remained very calm during this part of the interview.

Participant nine had a clear understanding of what was wrong with him and during the interview used medical jargon freely and in context. He said *"I went in there a I had a resection of my mitral valve which was obviously weeping pretty badly and one of my coronaries was occluded, my anterior one so they replaced that one.."* (Page 1, lines 10-12). He had been given information from the medical staff and clearly perceived the severity of his situation.

Participant ten summarised his history of symptoms and was aware of the difference between angina and a myocardial infarction. *"Yeh I had been on medication for blood pressure, cholesterol etc since I had me bypass or prior to me by pass in 1999 so like I say I had been having these chest pains for about two months but did nothing about them just thought a bit of angina and they'll go away but this Monday I knew something was wrong a bit crazy I know but I know I had me heart attack..."* (Page 1, lines 9-13). Despite this awareness he stalled help for at least half an hour. Despite his perception of what was happening he still did not want to believe the seriousness of the situation.

The participants described their perceptions in depth. They were aware of what was happening to them once they went to their GPs or hospital. They were able to summarise their medical care and understood the implications from the diagnosis. Their accounts support the 'established self' and 'threatened self' but show they are also able to see ahead to the 'towards the adjusted self' part of their recovery. 'Towards the adjusted self' is the life re-adjustment following a cardiac event, whereby participants develop a re-appreciation, re-energising and re-assertion of the Self.

#### **5.2.4 Cardiac rehabilitation inhibitors**

Within this theme participants explained their perceptions of cardiac rehabilitation and how participating would not meet their health needs. They provide clear arguments about the reasons why they did not attend. All had received written and verbal

information but they differed in remembering the format of this. Everyone who had a myocardial infarction had been given the Heart Manual, angina the Angina Plan, and cardiac surgery the Revascularisation Plan. The written information provides consistency from a health professionals' point of view but the participants had views about cardiac rehabilitation that were already established and these will be explored. Also in this theme is the participants' expression of a dislike of groups and isolation.

Participant One explained during the interview how he had been given written information and verbal information from the medical and nursing staff in hospital but he did not want to attend cardiac rehabilitation. One of the reasons he gave was that he felt he was physically active at work, and would prefer to do things alone. He thought that rehabilitation staff would annoy him, claiming *"can't stand people fussing over me"* (Page 2, line 9).

Participant two felt the information from the cardiac rehabilitation nurses in hospital and the community had been informative, but he was not offered cardiac rehabilitation sessions. He was asked what he thought it entailed and he said *"I think it would be exercises and that"* (Page 4, line 8). He did not feel it would help him as he suffered mental health issues. In his nursing records, the community specialist nurse had recorded that he had been offered cardiac rehabilitation and given an explanation of what this entailed.

Participant three, like participant one felt that cardiac rehabilitation would involve people making a fuss of them *"I don't believe in anyone coddle waddling yer"* (Page 3, line 20). She believed it was something that was done in hospital and perceived cardiac rehabilitation as *"Its going down to the hospital and doing a few exercises and that and I thought I wander around don't I and I can't be bothered with hospitals"* (Page 3, lines 13-14), at which point she changed the subject to talk about her sister. Later in the interview cardiac rehabilitation was highlighted again. She was asked if she felt attending rehabilitation would help people get better and she responded *"No I think they'd be worse off"* (Page 5, line 14).

Participant four had been informed about cardiac rehabilitation in hospital and he explained this as *"basically group therapy at the hospital talking about the same thing we*



are” (Page 3, line 2). When asked what put him off attending rehabilitation he said *“Well I have plenty to do when the wife’s out you know what I mean. I help around the house and look after these when they are off (points to a picture of his six children)... (Page 3, lines 9-10). He said that if it was on the internet he would give it a try, but would not attend group sessions.*

Participant five tried cardiac rehabilitation, but only attended one session. She said when she entered the small room where the patients had gathered *“everyone else in there is about one hundred and forty years old or hundred and sixty and here’s me only one hundred and two and I’m the one walking in and trying to get me breath and that” (Page 4, lines 26-28). Asked later if it was the other patients’ ages that put her off attending she said “No cos there was people there younger than me. Half the lasses I go to Bingo with, their husbands were there” (Page 5, lines 13-14). She goes on to argue “What the hells the point. I’ve got better things to do with my life then sit there and I can’t do the exercises they do, I’d have to do my own concoction that I do with the arthritis” (Page 5, lines 24-26).*

Participant six was offered cardiac rehabilitation but declined. He saw the benefits of it and described these as *“Well you meet different people who maybe have different ideas of what they do to improve themselves. I think you probably try a bit harder if you are involved in a group, probably like weight watchers.....Really though I don’t think I could have done more than I’ve done now but you have to be dedicated to do it obviously. You can’t think I’m not going to do it tonight or I’ll do it next week, you have to keep going” (Page 2, lines 31-34, Page 3 lines 1-4). Participant six had, in his view met his health needs himself and demonstrated motivation and commitment to his programme of physical activity. In later themes he shows what has driven him to make the changes.*

Participant seven felt some of his health needs had been met but not all. He was offered cardiac rehabilitation but declined. He has never been given a follow up appointment with the hospital, despite being told this would happen, but his GP had helped him access smoking cessation with the practice nurse. He was keen to return to work as he was the sole earner in the home and did not receive sick pay.

Participant eight could not access cardiac rehabilitation because he was nursing his dying wife with the help of his son. He said *"We just want to be here together"* (Page 2, line 3). His son helped him with his medication and took him for daily walks. His son had offered to take him to the rehabilitation sessions but he felt that he needed to be at home. He is also Polish so the language barrier was an issue. Although he speaks English he does not always feel confident about his understanding of what is said.

Participant nine was pleased with all aspects of his care and felt it met his needs throughout his journey. He was offered cardiac rehabilitation but declined, he said *"I don't like being regimented"* (Page 3, line 30). He wanted to get back to normal life without the fuss saying *"I didn't feel I needed it and I didn't want to talk about my condition. I wanted to get back to normal. Life is for living"* (Page 4, lines 4-5). He felt that at home he could manage his own physical activity and lifestyle changes.

Participant ten was particularly pleased with his follow up in the community with a community cardiac nurse but could not remember if he was offered cardiac rehabilitation. Due to other health problems he felt that rehabilitation would not have helped him saying *"the problem I've got with it is I've had surgery on me spine and problems with me legs etc so I think I'd have stayed away from that anyway cos I'd have generated more pain in me legs etc"* (Page 4, lines 12-15). In the nursing records the community cardiac nurse had documented that he had been offered cardiac rehabilitation but had declined.

Participants expressed a dislike of groups as an inhibitor to attending cardiac rehabilitation. Seven of the ten participants expressed this as a concern. Participant one was asked about his concerns about cardiac rehabilitation. He said *"I wouldn't like groups I don't think, prefer to do it on my own my own way, can't stand people fussing over me"* (Page 2, lines 8-9). He was asked why he thought people did attend the sessions and he replied *"They might not need the money might enjoy indulging their illness and wallowing in it. I prefer to ignore it and get on with it"* (Page 2, lines 15-16).

Participant two said he was not offered cardiac rehabilitation but he would not attend due to a dislike of groups and other health reasons. He was asked what would put him off attending and he said, *"I suffer with my nerves and depression like and I don't like being with a lot of people you know. I feel like they'd be talking about or something like that"*

*you know yeh and really I'm frightened of open spaces"* (Page 4, lines 12-15). He was asked why he thought other people attended cardiac rehabilitation and he replied *"Well theres a lot of people nosey aren't there and they like to go to see whats going on and they maybes only go a couple of days. There's a lot of nosey people about"* (Page 5, lines 4-6). He had previous experience of rehabilitation groups for his depression and this had, in his opinion made him worse not better, preferring to do things on his own. He said *"but like I say it did us no good so I came away"* (Page 5, line 20).

Participant three was offered cardiac rehabilitation but declined. She prefers to do things on her own. She was asked if she would attend if the sessions were not in hospital, she replied *"I don't suppose so 'cos I can't stand being hemmed in. That's why I keep me door open and its open on a night too....I like to feel free. Probably the way I was brought up in that home"* (Page 3, lines 24-27). Other health conditions also influence her decision not to attend cardiac rehabilitation, she has asthma. She was asked if she thought people benefit from cardiac rehabilitation and she responded *"No I think they'd be worse off"* (Page 4, line 14).

Participant four was offered cardiac rehabilitation but declined. He said *"I'm not one of these type of people who can sit and talk about it really. I just want to get on with me life basically.....I'm not really a group person I've always been on me own y'know and I've got me family and they keep me right"* (Page 3, lines 19-22). He was asked why he thought other people attended rehabilitation and he replied *"People who haven't got a big family, people who are lonely yeh people who haven't got a big family"* (Page 3, lines 35-36).

Participant seven was asked what he thought cardiac rehabilitation was, he said *"Its exercises isn't it like in a group"* (Page 2, line 34). He was offered rehabilitation but declined. He was asked what his main concern was about attending and he replied *"there would have been old people there and I'm not one for groups, I'm more for the family and we do things together"* (Page 3, lines 5-6).

Participant eight declined cardiac rehabilitation due to his home circumstances stating *"I think some people like to be in a group and talking to other people, but at the moment*

*my wife is sick and I need to be here. My son wanted me to go and he would have taken me but I just didn't want the (long pause) fuss".*

Participant nine was given written information about cardiac rehabilitation but declined. He has a small holding and was busy at this time of the year looking after his land. He also had other health problems that he thought would restrict him in the exercises, he has serious back problems. Asked if anything would have influenced him attending he said he did not need it. He was asked what he thought made other people attend and he said *"Some people are more gregarious than I am, I think that's the answer. I mean I join in with people when they are doing something I want to do but just to go and be with people just for the sake of it seems a waste of time... I mean at my age after a meal I like to have a lie down"* (Page 4, lines 7-14).

Isolation was a factor for the participants. This was most noticeable, but not exclusively in those participants who lived alone. Of the ten participants, three mentioned isolation. Current cardiac rehabilitation programmes may not offer isolated patients an appropriate service at present.

Participant two has lived alone for the last five or six years without any family or friends. He had depression for fifteen or sixteen years since the death of his mother and felt more at ease with his own company. He said *"I suffer with my nerves and depression like and I don't like being with a lot of people you know. I am under the doctor for that"* (Page 4, lines 12-13). He stayed in his flat most of the time but did go to the shops and for walks. He used to go to his local pub each night for a drink but had stopped this following his cardiac event to reduce his alcohol intake. When he did go he would sit alone and did not socialise easily with others.

Participant three was brought up in a children's home and felt better on her own than in large groups. She said *"I've always been by meself you know and I've learnt to do things my way"* (Page 4, lines 7-8). Later she describes her upbringing which had influenced her life *"I mean we were brought up in a home and when we were sixteen that was it, that was it we had to fend for ourselves"* (Page 4, lines 16-18).

Participant ten also expressed isolation. He had been in the army and had suffered post traumatic stress disorder from his time in Northern Ireland. This has had an impact on his life and his ability to mix with other people. He said *"The problem I've got is the fact I have a death wish and am not bothered about living. I only get me medication once a week cos I'm on a high risk for self harm"* (Page 5, lines 6-8), when asked about harming himself he replied *"Yes eight times but its been a long time since the last time, how many years, must be two years"* (Page 5, lines 10-11). Asked about friends he said *"Umm when you say that I used to have a lot of friends but when I stopped playing golf they just disappeared and I knew they were just acquaintances and I only have a couple of friends around me and I rarely see people"* (Page 5, lines 21-23).

The inhibitors to cardiac rehabilitation focused on the awareness the participants had of cardiac rehabilitation and what it entailed. The perceived benefit of cardiac rehabilitation to enabling participants to achieve lifestyle goals were not seen by them, focusing on the harm that attending could do them. Those participants who felt isolation did not want to attend as they preferred to be alone and some did not like groups. Participants felt that cardiac rehabilitation was indulgent to those who liked to focus on their illness instead of returning to normal life.

All the participants had preconceived ideas about cardiac rehabilitation that they had read about, learnt from others or had internally generated themselves. They saw rehabilitation as harming and not enabling recovery. The participants negotiated non-attendance by making lifestyle choices and changes without healthcare professional guidance or support. Participants felt that cardiac rehabilitation would disrupt their routine patterns and stayed within the 'established self' element of their recovery within this theme. They did not see rehabilitation as enabling them to move towards an 'adjusted self' but as a continuation of the 'threatened self'.

### **5.2.5 Quality of Life**

Eight of the ten participants mentioned quality of life in their interviews. This is an important issue for people following a diagnosis of heart disease as it has an impact on their daily living and outcomes for the future. A summary of their thoughts is described within this section.

Participant three said there had been an improvement in her quality of life since having the myocardial infarction. She said *"I didn't feel ill, in fact since I had the heart attack I can walk down that street without difficulty. You know with the asthma I still get short of breath but I'm not the way I was but it might be the tablets helping me"* (Page 2, lines 6-8). Asked if she took the medication she replied *"Yeh four in the morning, yeh they prevent problems and are really important, I'm better since I started them tablets"* (Page 2, lines 10-13). Asked how she had coped since her diagnosis she replied *"I never really let it bother me. I'm not one of them that likes to brew over things I just get on with things. I always have"* (Page 2, lines 15-16).

Participant four was asked if his diagnosis had changed his life and he responded *"Phoor difficult to say really umm I can't get out as much now umm I have to be careful what I eat so me diet has changed, no more drink or whatever although I wasn't a big drinker anyway really, no more socialising in pubs or owt uhh just made me think a lot more about looking after meself keeping meself right with eating the right stuff like oily fish and vegetables"* (Page 2, lines 9-13). He showed a mixed response to his quality of life and felt it had restricted his social life, but realised the need for change.

Participant five also expressed positive and negative effects on her quality of life. She said *"I'm going to live my life. I'm not going to sit around fretting and worrying about it. I want to enjoy it. I've got a husband, three girls and we are going to make sure what we've got is quality time ....I'm not sleeping on a night like I used to, I'm tossing and turning all night"* (Page 4, lines 19-25).

Participant six had felt an improvement in his quality of life. He experienced less angina and felt the changes he had made have improved his life. Asked if he felt better he replied *"Definitely I feel a lot better for it, a lot fitter"* (Page 2, line 8). He embraced the lifestyle changes to improve his quality of life and took control of his health in a positive way.

Participant seven had experienced a financial impact due to his myocardial infarction that had an impact on his life. He worked in a manual job where he received no pay if he was off. This had an impact on both him and his family as he had two small children to support. He said *"I don't get any pay when I'm not at work so we've been down to try and*

*get some benefits and see what we can get but it takes time and there's loads of forms and things"* (Page 1, lines 22-24). He experienced pressure to return to work before he was fully fit and was unable to return on a phased return as much of his work was away from home.

Participant eight had improved his quality of life following his myocardial infarction. He said *"At first I could only go around the corner but now I can go around the block. I can't go fast and I have to keep taking breaks to catch my breath but I am better"* (Page 1, lines 23-25). He was positive about his recovery and he was able to set himself realistic goals within his lifestyle.

Participant nine felt his quality of life was returning to normal following heart surgery. Three months after his operation he said *"now I'm chopping away, cutting trees down"* (Page 3, line 20) on his piece of land. He felt it took ten weeks to get back to this stage of his recovery. His ambition following the surgery was to be able to keep his small holding of land and be able to look after it himself.

Participant ten had found his health deteriorating and he was restricted on what he could do, having a negative impact on his quality of life. He said *"I find I can do even less now, the minute I start doing anything me angina comes on. I mean I went into the town this morning and I can only stand so long in town because of me PTSD but I went to two shops one in the Cornmill and one outside the Cornmill and that was enough for me and I just took it steady so my angina wasn't too bad but once back at the car I had to take a blast (GTN spray)....I have to be careful doing other things like I say just getting up and doing things and I just can't and it makes me even more aware that my life is deteriorating in such a big way that I can't handle it you know what I mean. I have a sixteen year old head on me shoulder well twenty one and my body is not that age anymore"* (Page 10, lines 1-9).

Some participants were able to return to a good quality of life without the benefit of cardiac rehabilitation, some felt there was no difference and others felt that since their cardiac event, their quality of life had worsened. The decisions they had made were based on the information they had received and negotiating the best ways to improve their quality of life to enable their life re-adjustment. The journey from the 'established

self' to the 'threatened self' and 'towards adjusted self' in order to improve quality of life for participants was not achieved by all. Those participants who felt their quality of life was worse since the cardiac event had continued to stay within the element of the 'threatened self', unable to move towards adjustment. Those participants who had successfully improved their quality of life managed to journey 'towards adjusted self' without the input of cardiac rehabilitation, through self determination and motivation.

#### **5.2.6 Fear and Shock about the Diagnosis**

Fear and shock was found to be a significant theme for participants. This was reported by participants at the beginning of their cardiac event but continued to be an issue in their recovery. Phase three cardiac rehabilitation programmes are designed to address this issue through information giving and support, but as these participants did not access this they had to come to terms with these fears alone. Of the ten participants five mentioned their fear and shock at their diagnosis.

Participant one was asked how he had coped with his diagnosis and he replied *"I was shocked, frightened but didn't want to stay in hospital, just wanted to get back to work"* (Page 1, lines 23-24). He was asked what he was frightened of and he responded *"That I would have another heart attack, the pain was terrible so I was frightened of getting the pain again"* (Page 1, lines 26-27).

Participant two was asked if the diagnosis was a shock and he replied *"Yes, aye it was cos I have never suffered nothing in my life never been in hospital"* (Page 1, lines 18-19). Participant four was asked if he had a new lease of life since his heart attack and he responded *"Oh yeh it was getting over the shock more than anything I think and realising how many tablets I was having to take each day, that's when it hits home like and the fact you will be on them for the rest of your life too"* (Page 4, Lines 8-10).

Participant five was asked how she had coped with the diagnosis, being a young woman. She said *"So yes it was a shock when you think of everything you try to do y'know you're not a drinker, you manage to this and that and then bump you've got a heart attack on top of everything else"* (Page 3, lines 123-25). She was philosophical about it though and insisted it was not going to get her down and affect her life. She said she had a heart attack when she was fifteen and said *"I got a common cold and I got*



*bronchitis and the pleurisy and I ended up in coronary care after having a heart attack. They didn't think I was going to survive it, I was that ill with it and they even filled all me death certificate out just ready to put the signature on the bottom but somehow I bounced back"* (Page 3, lines 17-21).

Participant seven described how it felt for him after he discovered he had experienced a myocardial infarction. He said *"Well it was a big shock. You expect these things when you are older but I'm only in me 30s and as you know I have a very young family so, yeh scared"* (Page 1, lines 17-19). When asked how he coped with it he replied *"Well at first I was scared it would happen again, I was scared to do anything and wasn't sure what I was going to do"* (Page 1, lines 21-22).

Fear and shock of the event and the potential for a re-event affected participants in the study, affecting all age groups and genders equally. They gave frank and clear accounts of how the cardiac event had affected their psychological well-being as well as fear for their families. Fear and shock could potentially be a barrier to getting 'towards the adjusted self'. If managed ineffectively the fear and shock experienced could promote a mal-adjustment to life after the cardiac event, reducing the possibility of re-appreciation, re-energising and re-assertion of the Self.

### **5.2.7 Choices and risks**

Choosing or rejecting lifestyle changes was a factor for participants in this study. They made choices based on their perception of risk versus benefit. They contextualised appropriate changes within their everyday lives, rather than engaging in a structured cardiac rehabilitation programme. Following their diagnosis eight of the ten participants described their health choices and risks. They described lifestyle changes they had chosen to make and risky behaviours they continued with and their reasons for doing so.

Participant one read all the leaflets he received from the hospital rehabilitation nurses and decided on making some changes. He described the changes he had made *"I used to drink a lot but now I am within the 21 units a week. I have always ate healthy but I watch it more now. I lost 10 pounds in weight. I walk the dog and I have bought a stepper thing"* (Page one, lines 40-42).

Participant two had made a number of changes by exploring the risks and choices he needed to make. He had cut down his alcohol intake, increased his physical activity and given up smoking. He said *"Well I was going out 3 times a week before and I was drinking a lot but now I'm only going out once and also I've stopped smoking, I stopped smoking the day I went into hospital"* (Page 2, lines 14-16). He describes how he drank 10 pints a day three times a week and smoked 20 cigarettes a day. He had increased his physical activity by daily walks and decorating his flat.

Participant three had negotiated changes to her lifestyle but continued to take some health risks that could be detrimental to her cardiac health. She said *"I've cut out me sugar. I have that what d'you call it, slender and I've cut out me white bread and I take brown bread uhh that's really about it"* (Page 2, line 21-22). Asked about her smoking and whether she had reduced the amount of cigarettes a day she replied *"Oh don't mention that, nooo I think I'm having another heart attack if I don't have a cigarette"* (Page 2, lines 32-33). She did not increase her physical activity and did not drink alcohol.

Participant four had started eating a healthy diet but not increased his physical activity due to problems with circulation in his legs. Asked about cigarette smoking he replied *"Yeh I have cut down on them absolutely umm well alcohol I've never bothered with, anything fatty or fried yeh"* (Page 2, lines 20-21).

Participant five drank very little alcohol and ate a healthy diet. She and her partner gave up smoking after the myocardial infarction. She said *"I gave up smoking in November...we both went to the smokers clinic and he gave up with me...he went cold turkey and I managed to give up with champix"* (Page 4, lines 8-14). She gave up taking her medication due to the side effects without consulting a doctor she claimed *"They've got me on medication to keep my BP low but I already suffer a low BP and you feel like your toes have been chopped off and all drained so get rid of it, I don't need it, I don't want it. Slightest ooze or scratch and I'm pouring blood they've got me on these ones, get rid of them I don't need it. I finally get rid of them"* (Page 5, lines 28-33). She had a clear understanding of why she was taking each tablet but made an informed choice to stop them.

Participant six had lost two stone in weight since his diagnosis of angina. He had changed his diet and improved his physical activity. He had never smoked cigarettes. He said *"Well I get more exercise, a low fat diet, no salt or virtually no salt, get more walking and basically just I keep meself fitter"* (Page 1, lines 29-30).

Participant seven had started eating a healthy diet but found giving up cigarette smoking a problem. He went to see a nurse at his GPs but still was unable to stop. Going back to work had not helped him with this as he said *"Its harder since I've gone back to work as I share a van with a fella who smokes all the time and sometimes I just have to have one, it was easier at home. In fact most of the lads at work smoke"* (Page 2, lines 13-15). He understood the risk of continuing to smoke but making the changes was a challenge for him.

Participant ten admitted to eating a *"horrendous"* (Page 4, line 25) diet, was unable to undertake physical activity due to other health conditions and continued to smoke. He said *"I know I'll have to stop smoking but then again I have a reason to smoke but I would endeavour to do that but again whether it happens I don't know"* (Page 7, lines 1-3). He had previously stopped smoking for 6 years and so was confident he could again if he wanted to.

Making lifestyle choices and choosing the most achievable for them was an issue for participants. They negotiated what changes they were willing to make, what changes they would not make and what could change in the future. This was only partially influenced by others, either health professionals or family, but predominantly by themselves and their belief they could or wanted to change. The participants' journey from the 'established self' where lifestyles were adopted 'towards the adjusted self' where healthy choices could become part of their normal lives was a challenging part of their recovery. The 'threatened self', the shock of the cardiac event could have a possible outcome for effective lifestyle changes, or it could encourage participants to engage in a fatalistic approach to lifestyle management, depending on the participants' experience.

### 5.2.8 Support

All the participants discussed support in their interviews, and this can be divided into formal and informal support. The formal support was that given by health professionals and the informal was by family and friends. This proved to be an important theme to the participants, having an impact on their recovery. The appropriateness or non appropriateness of the support given, at a time that would benefit a positive health journey from diagnosis was an issue for the participants. Coming to terms with the threat of the cardiac event and re-establishing their self was different for all the participants, but the health interventions were given at set times within their recovery. Family or peer support was given to some, but without any direction or training on how best to employ this help effectively.

Participant one was asked about what support he had received from family and friends and he replied *"I prefer to get on with things myself, I don't want their support but my daughter keeps telling me what I should be doing and I just say leave me to get on with it, she says I am pig-headed"* (Page 1, lines 28-30). He was more willing to take support from professionals and found the community nurse helpful, saying *"A nurse came to see me. She was very good and answered all my questions, I found it helpful"* (Page 1, lines 35-36).

Participant two had no family or friends to support him, but he got support from his GP and a community cardiac nurse. He said *"Ahh anyway it was the doctor from the other surgery what come out and explained what I had to do with the diet and this that and the other"* (Page 1, lines 14-25). Asked if he found the support from doctors and nurses lacking in any way he said *"No I got plenty of support. I had to go and see the Irish doctor"* (Page 2, line 3). He was seen by cardiac rehabilitation nurse whilst in hospital who showed him a video about angiograms and he had found this really useful. He was transferred to the tertiary hospital for further treatment and found the care very good there. On discharge a community cardiac nurse came out to facilitate the heart manual and gave him her contact details.

Participant three had some support from family, going to her daughters each day for tea but she said *"You can't be putting on them"* (Page 2, line 18). She did not mention formal support although she did have an appointment with her GP in the near future. Participant

four was admitted to coronary care following his myocardial infarction. He described the doctors and nurses as *“.putting needles into me and talking to me....they were very good though... reassuring, nice to know someone was there for you”* (Page 1, lines 18-21). He was visited in hospital by the cardiac rehabilitation nurses who gave him verbal and written information. Once home a community cardiac nurse visited him, asked if this was helpful he replied *“Yeh she took me blood pressure and that and explained a couple of things I wasn’t sure about, yeh it was fabulous”* (Page 2, lines 1-2). Informally he had a lot of support from friends and family saying *“Yeh it was as much a shock to them as it was to me, but everyone has been fine, fabulous”* (Page 2, lines 6-7). Asked if he felt he had enough care and support he answered *“Yeh oh yeh more than enough I couldn’t fault it absolutely fabulous”* (Page 4, line 1).

Participant five had a negative experience in hospital and felt unsupported throughout, discharging herself before all the tests had been completed. She described her experience as *“They put me on an ECG and wanted a few electrolytes and stuff. Five minutes later everyone deserted me, half eight came, nothing, nine o’clock came, nothing, ten o’clock came, nothing.....not even a nurse had been to see you alright, are you still in pain, absolutely nothing....quarter to eleven I said that’s it and when I walked out of the room theres five of them up at the desk with their feet up drinking.... They said but the doctors busy and I said fair enough the doctor can be busy for a couple of hours but for yours lot to be sat up here and not one person even to come down and say are you alright...so of course I came home”* (Pages 1, lines 28 -34, page 2, lines 1-13). Her family provided good support to her *“If I need anything then they are all there”* (Page 3, line 33). Since returning home had she received any support from nurses and doctors? *“Absolutely nothing...we got a nurse down from Piper House and she came a couple of times talking through basic things and she said there wasn’t anything else she could do until you’ve had the angiogram done. Once you have had the angiogram done I’ll come back to you”* (Page 5, lines 4-10). She never returned to see her. She found the heart manual useful and gained support from this saying *“Yes I’ve found that very useful because with the manual it is all broken down into stages. You can go through the stages”* (Page 7, lines 32-33).

Participant six found the support from doctors and nurses useful and he was given written information. He had good support from family and friends. He did not elaborate on the theme any further than one word answers, but seemed pleased with his care.

Participant seven was given a heart manual in hospital by a nurse who talked to him about diet and smoking. Asked about his support from doctors and nurses he said *"Good I s'pose but it all happened so fast I didn't take it all in"* (Page 2, line 1). He was promised a follow up appointment at the hospital but never received this but he did find the care in primary care supportive saying *"My GP has been good and the smoking nurse but I would have liked some help with this weight as it just keeps going up. The follow up here has been good and being able to talk to someone about what has happened"* (Page 3, lines 18-21). His family were a great help to him saying *"We are a big family and they are all helping....she is (wife) is making healthy food and encouraging me"* (Page 1, lines 30-33).

Participant eight received the heart manual and his son read it with him. He had been seen by his GP and a community cardiac nurse visited him at home to give him advice on *"Walking and diet and tablets"* (Page 1, line 14). The nurse had mentioned cardiac rehabilitation and its benefits. Most of his support was from his son and he says *"My son has been very good, he looks after me and my wife who is very ill, she has terminal cancer and he gave up his job to look after us, he is very good... my son takes me for a walk every day...my son cooks for us and we eat very healthy, lots of vegetables"* (Page 1, lines 16-21). His son gave him his medication. Asked about what he thought of the care he had received participant eight said *"Fantastic, excellent, everyone has been very kind"* (Page 2, line 17).

Participant nine had a mixed experience of support from doctors and nurses. Whilst in hospital he said *"if you want to ask a question you have to wait for the registrar to come round and it might not be that day and so on but yes eventually they were pretty good"* (Page 1, lines 23-25). His family lived in Worcester and London but they phoned the hospital regularly, spending *"£150 on phone calls"* (Page2, line 2). At times his support was too much and overwhelming, he said *"So yeh they were pretty attentive, particularly one daughter and one cousin of mine too. She was a bit of a nuisance to me and the hospital and still is"* (Page 2, lines 2-4). He was visited at home by a community cardiac

nurse who rang up following his operation and visited, *"She was very attentive"* (Page 2, line 23). He said he was happy with his follow up.

Participant ten was particularly impressed with his care following discharge. A community cardiac nurse visited him four or five times, every couple of weeks after discharge. He said *"Anyway he came out and was very good...he came out and spoke to me and asked what was happening this that and the other umm he organised the doctor to give me some of the medication to try and control the angina...yeh he took me blood pressure etc and kept me informed what was happening and what could be happening. I got the most information off him then I did from the hospital"* (Page 3, lines 14-18). He went on to say *"Ok I was in the chronic care unit (Coronary care unit) in the hospital but they didn't come and say this is this and this is this. I didn't know me left ventricle had been damaged till (name of nurse) told me and that it had stretched or something and its harder to pump the blood through but yeh the support afterwards was spot on. I'm not saying the care in hospital was bad cos the nurses did their job but (name of nurse) finished the job off"* (Page 4, lines 2-7).

Support, whether formal or informal was present for participants if they wanted to accept it. Some relied on family, friends or health professionals whilst others preferred to be alone to deal with their own health and well-being. Others felt they had not been given enough support from health professionals but had managed to readjust with their family to guide them through their health journey. The appropriateness and timing of the support could enable or hinder participants through their health journey from the 'established self', the 'threatened self' and 'towards the adjusted self'.

### **5.2.9 Change Drivers**

What drives a person to make lifestyle changes and how they negotiate what changes they are going to make, the method for doing so and the support they have sought is important in the management of long term conditions. Eight of the ten participants mentioned change drivers in their interviews.

Participant one was asked what changes the diagnosis had made to his life. He had reduced his alcohol intake to within normal limits, lost weight, walked the dog and bought a stepper exercise machine. He had previously made significant changes in his life but

despite this he still had a myocardial infarction. He said *"I gave up smoking 4 years ago and got high blood pressure and stopped drinking so much a few weeks before my heart attack and then I had a heart attack"* (Page 1, lines 39-41).

Participant two reduced his alcohol intake after his myocardial infarction, given the impetus by having the diagnosis. This change had the benefit of improving his weekly units of alcohol but the negative effect that he did not go out to the pub so much so became more isolated at home, without people to talk to. He also managed to give up smoking following his diagnosis saying *"I had 10 packs of baccy in the house so I got rid of them, kicked them out of the way because I knew if they were in you know, way I sold them to me mates like and from that day I went to hospital I cut it out, I tried before you know but I couldn't. I get over the worst now though"* (Page 2, lines 20-23).

Participant three explained what changes she had made since her myocardial infarction and the reasoning behind these decisions. Although she improved her diet, her physical activity and smoking status had not changed. She was aware these were risk factors but had balanced the need for change and what she was practically able to do. She improved her diet to lose weight as she felt this was something she needed to do *"I haven't lost a pound so it's not made any ruddy difference"* (Page 3, lines 10-11).

Participant four had changed his diet to a healthy one post myocardial infarction. When asked about his cigarette smoking he said *"Yes I have cut down on them absolutely"* (Page 2, line 22) but did not elaborate on how many a day he was smoking. After the interview was completed he said he continued to smoke cannabis, believing this was less harmful than cigarettes to his cardiac health.

Participant five already ate a healthy diet due to being diabetic but after her myocardial infarction she decided to give up smoking as it was *"the only one thing I have been able to do for myself"* (Page 4, line 5), but also said later *"Nobody can turn around and say you're going to give up smoking and live longer you just don't know, you don't know whats in store for you but you can't just sit around and say well I'm not going down town because the pressure its going to cause. If it's going to happen it's going to happen"* (Page 4, lines 16-19). The heart manual had been a significant change driver for her



saying *“they give you a guide in that book on what you can do yourself to make things better for yourself. It’s nice cos you can do it in your own leisure”* (Page 5, lines 7-9).

Participant six was asked how he motivated himself to make changes in his lifestyle and he replied *“Just will power to be honest...if I want to do it I will but sometimes you are a bit lazy and don’t want to do it but I don’t want to die. I mean its to my benefit as far as I can see cos the less weight I am carrying then the less chest pain”* (Page3, lines 21-24).

Participant seven had used the heart manual as a driver to enable him to prioritise the changes he needed to make. His wife, he said *“has been making healthy meals with pasta and such like but I’m still hungry. The smoking is a difficult thing”* (Page 2, lines 7-9). Participant eight endeavoured to make changes following his myocardial infarction to his diet and physical activity. His main driver had been his wife’s illness and the need to be well for her *“my wife is sick and I need to be here”* (Page 2, line 12).

Change drivers to make lifestyle changes ranged from the written material they received, will-power or family support. One of the main drivers for change was the fear of a re-event and possible death. As participants accepted what had happened to them they were better equipped to manage the changes to their lifestyles. This enabled the re-appreciation, re-energising and re-assertion of their Self through change management and control.

#### **5.2.10 Fear of Hospitals**

The fear of hospitals theme was not found in a large number of participants, but in those that expressed this issue some interesting data emerges so it has been included as a theme. Two of the ten participants were frightened of hospitals. Participant one said *“they said I had a heart attack and the next 48 hours were crucial but I said its too late for that, I had been at work since it happened so I discharged myself, I only stayed in 8 hours, enough for me, I hate hospitals, I don’t like going in them as they are where you go to die .....I just feel if you are ill you need to get on with it”* (Page 1, lines15-21).

Participant three also expressed a fear of hospitals that affected her care. She discharged herself after three days. She said *“Yeh I don’t want surgery. When I had me gall bladder done they had to give me valium. I was a bugger and ran out”* (Page 4, lines

27-28). Asked if she was frightened of hospital she replied *"Yeh terrible.....I used to work in hospitals. I used to love the job....and I really enjoyed that job but its just the thought of the unknown"* (Page 4 line 29, page 5 lines 1-4).

Although not expressing any fear of hospitals participant five discharged herself from hospital because she was not happy with the care she was receiving. Participant ten delayed going into hospital when he was having a myocardial infarction, once there he stayed and received treatment.

The fear expressed about hospitals is interconnected with participants' fears of the event itself, the fear of further events and medical intervention, the 'threatened self'. Participants saw cardiac rehabilitation as harming, not enabling a recovery, and similarly saw going into hospital as a weakness or failure.

#### **5.2.11 Time and financial restraints**

This theme reflects the socio-economic status of the participants. Those in work were in low paid employment with little or no sick pay so when not working they were exposed to financial consequences. The participants who did not work found that time constraints were important as they had responsibilities within the family that needed to be met.

Of the ten participants six stated time or financial restraints as their reason for not attending cardiac rehabilitation sessions. Participant one worked as a plater for the steel industry and travelled all over the country in his work. Asked if why he did not attend cardiac rehabilitation he said *"I can't do that because of financial reasons and the sessions are always during the day. I hate hospitals too. I do plenty of exercise at work"* (Page 2, lines 1-2). The community rehabilitation sessions were mentioned to him but he replied *"I earn £15 an hour and work out of town a lot so it would mean me losing a lot of money to go to them what with the travelling too. I only get basic sick pay its about £52 a week, not enough to live on"* (Page 2, lines 4-6). He was asked about his concerns about cardiac rehabilitation and he responded *"Financial and timing but I wouldn't like groups I don't think, prefer to do it on my own my own way, can't stand people fussing"* (Page 2, lines 8-9). He was asked if he would attend sessions on an evening or weekend and he replied *"No, prefer to do my own thing wouldn't have gone"* (Page 2, line 13).

Participant four did not want cardiac rehabilitation because of his dislike of groups but he also expressed concerns about time. Asked why he thought people went to the sessions he replied *“people who have more time than me”* (Page 3, line 31). He said he would not go to a one to one session but would consider cardiac rehabilitation on the internet saying *“Yeh I’m alright on the internet yeh I could maybe use that (Pause) yeh I would give that a try”* (Page 3, lines 25-26). Asked what could be included or improved to encourage people to attend cardiac rehabilitation he suggested transport being offered and help with social security.

Participant five was a mother of three school age children and she said *“Because you were going there and it didn’t start until like 3 o’clock in the afternoon. My kids come out of school at ten to three on a night. They come home and expect to find their mother there. We like to have our tea”* (Page 6, lines 17-19). Asked if it was changed would she attend she replied *“The timing was definitely very off putting”* (Page 6, line 29). She did attend one session but did not enjoy it.

Participant six worked as a manual worker, travelling with his work around the country. He said it would be hard for him to attend cardiac rehabilitation arguing *“It’s quite hard to find the time to go twice a week, because as you know I work in various locations which could be an hours travel either way kind of thing. I don’t think me employer would be too keen on me coming along on a dinner time twice a week for 2 months. I would have liked to have done it but obviously when you’re working you can’t do these things”* (Page 2, lines 17-21).

Participant seven worked in manual jobs across the country. Asked if he was offered cardiac rehabilitation sessions he replied *“I would have found it difficult to get there and I had to go back to work, I can’t afford time off work”* (Page 3, lines 2-3). Asked what would have made it easier to attend he responded *“Night times would have been easier I suppose”* (Page 3, line 9). If offered a one to one session he said *“Yeh that might have been ok. I wouldn’t have felt so self conscious”* (Page 3, line 11). He was asked what encouraged others to attend and he replied *“Maybe retired people who have time on their hands. I think also some people like to talk about their problems but I have me family for that”* (Page 3, lines 14-15).

Participant nine had been offered cardiac rehabilitation but declined due to the time. He said “....I thought I can’t afford it at this time of the year looking after the land. I’ve got a hedge I need to cut” (Page 3, lines 27-28). Financially he was secure but the time factor influenced his decision making.

Of all the themes, time and financial restraints was the only physical, practical one found. All the other themes had an element of psycho-social issues that impacted on participants’ health journey. Participants argued that time and financial restraints contributed to them not attending cardiac rehabilitation, with work or family commitments a factor in this. During the interviews when participants were offered alternative such as weekend or evening sessions, they said that they would still find it difficult due to working away or looking after family. Participants wanted to return to normal life, and for many the practical issue of providing for the family by working or looking after children was essential for their well-being and the stability of the family.

### **5.3 Interpreting the Themes**

The themes were further explored to examine the relationships with them and the participants. Analysis of the data allowed a deeper, richer insight into the study and the most relevant issues to the research question. The three themes that were the most significant were (1) support, (2) choice and risks and (3) cardiac inhibitors.

Support, both formal and informal from health professionals and family or friends had an impact on the participants’ coping strategies following their cardiac event. The participants had a range of experience from no professional support to excellent care, no social support to too much support from family and friends. It highlighted the need for professionals to provide advice, information and support in a patient friendly way so that they are able to understand what is happening to them. Family and friends in most participants provided good support during adjustment to their diagnosis.

Another significant theme that emerged from the data was choice and risks. Of the participants nine out of ten had made changes to their lifestyle based on what had happened to them. Only participant ten continued to live as he did before, he smoked, ate an unhealthy diet and did no physical activity, partly due to his other health problems. One participant gave up alcohol as he was a heavy drinker prior to his heart attack. Six participants improved their diet to include more healthy options such as fruit,

vegetables and brown bread and six improved their physical activity by designing an exercise programme that suited their needs. Two participants gave up smoking, two had not changed their smoking habit at all and two were cutting down how many they smoked a day. One participant was seeking help through his GP practice and the smoking cessation clinic.

Cardiac rehabilitation inhibitors were an important theme. All the participants felt that cardiac rehabilitation would not meet their needs and any changes to their lifestyle would be better done by themselves. They felt that rehabilitation would not enable recovery and possibly cause further harm.

Of the ten participants, seven can remember being offered cardiac rehabilitation and three either were not offered or could not remember. Participant six said, when asked if he had been offered rehabilitation *"No"* but then when asked if he was he was asked to come to a group he replied *"Yes I was invited to do that but with me working its quite hard to do"* (Page 2, lines 11-15). Participant seven also worked and felt he could not find the time to attend as he needed to get back to work. Participant ten was asked if he was offered the opportunity to go to cardiac rehabilitation programme and he responded *"I can't remember I am sorry"* (Page 4, lines 7-10). All those who were offered then made a choice to attend or not based on their situation, experience and perceptions of what it entailed. Participant one had concerns about hospitals, and when it was explained that he could do the programme in the community he expressed concern about the timing of the sessions and loss of earnings (Page 2, lines 1-6). Participant three also did not like hospitals and related rehabilitation with going to a hospital to do exercises. Participant two thought that cardiac rehabilitation consisted of *" well it was that they do different exercises and this that and the other"* (Page 3, lines 27-28). Participant four thought that cardiac rehabilitation was *" ...basically group therapy at the hospital talking about the same thing we are"* (Page 3, lines 2-3).

Participant five attended one session but did not enjoy it. She felt like the other patients were old, the timing did not suit her young family and she had problems with the exercises due to other health problems. Participant eight would have attended the rehabilitation if he was able to, but his wife was dying and he was needed at home to be

with her. Participant nine did not feel he had the time to do the rehabilitation and was concerned about being “*regimented*” (Page 3, line 31).

The main barriers to the participants accessing the rehabilitation were fear of hospitals, timing of sessions, financial costs and a dislike of groups. All thought that rehabilitation was doing exercises, and did not realise that it was a programme that involved other facets such as information, relaxation and support. Of the seven who could remember being offered cardiac rehabilitation all had made a choice not to attend and had clear reasons for their decision. The participants all had a good understanding of their diagnosis and their treatment. Each had experienced a different journey through the medical system but all had made their choices based on the information they had received.

All the participants experienced some level of loss or grief following their cardiac event. This will be discussed further in the discussion chapter. This highlights the ‘Established self’, ‘Threatened self’ and ‘Adjusted self’ journey they had all undertaken following their cardiac event, and will be further explored with reference to the Heideggerian approach used. In the next findings chapter are three case examples of participants’ journeys, joining the transcripts back together for their complete experiences.

#### **5.4 Summary**

The transcripts have highlighted a number of themes that participants felt were important to their journey from diagnosis towards the adjusted self. The three main themes that emerged were; support, choices and risks, and meeting health needs. The way they remembered being offered cardiac rehabilitation and the information they received enabled them to make a choice of whether it would benefit them or not. The main barriers to accessing phase three cardiac rehabilitation programmes were fear of hospitals, dislike of groups, timing and financial restraints. The transcripts gave rich data that was frank and honest, with participants seeing the researcher as a researcher, not as a nurse. They each have given a story that needs to be further discussed within the thesis, and related back to published literature.

The findings showed how the participants felt about their post cardiac event health journey from diagnosis to data collection. As a phenomenological study it enabled the

researcher to collect and analyse rich, in-depth data, giving the participants time and space to tell their experiences. The themes emerge into the three elements of phenomenology that applies to this study, these are (1) Established self, (2) Threatened self and (3) working towards the adjusted self. These elements will be further explored within chapter 7, discussion and related back to the research question and methodology used. In the next findings chapter three case examples will be presented to represent the complete cardiac health journey for the participants.

## **CHAPTER 6 - Findings Two**

### **6.1 Introduction**

In the previous chapter the data has been analysed through emerging themes and now three of the participants' experiences are described as case examples to further understand their beliefs and thoughts. The three participants chosen for the case studies have all had a myocardial infarction. Two of the participants were men and one a woman. The participants' names were changed to ensure anonymity. The case examples are presented from the participant perspective, collated and analysed by the researcher. The rationale for including case examples was given in chapter 4, research design and methods. This was that the value of case examples within the study illuminates new ideas, and allows the researcher to tell each participant's story in depth.

The three main themes that emerged from the data were (1) support, (2) choices and risks and (3) meeting health needs. These will be explored within the case examples linking the participants' journeys back to the 'Established self', the 'Threatened self' and 'Towards the adjusted self'.

#### **6.2.1 Case example One (Bill)**

The first case study is Bill, a 34 year old man who is married and lives with his wife, Tracey and their two small children in the poorest electoral ward of Darlington. He works as a manual worker installing air-conditioning units on a casual basis for his brother. He had his myocardial infarction whilst at work and was taken to hospital 20 miles from his home. He has no past history of chest pain and has enjoyed good health all his life. He had never been to hospital and rarely saw his GP. Bill smokes 20 a day, eats an unhealthy fast food diet of pies, chips and take-away and has a body mass index of 32. He used to be a body builder but gave it up 5 years ago after the birth of his first daughter and now does very little physical activity, apart from his job. Until his myocardial infarction Bill took no medication.

Bill describes how he was on a training course at work, inside a pipe when he experienced "severe chest pain". At first he thought it was claustrophobia and asked a colleague to help him out of the pipe. He had a pre-determined way of relating the event



to previous experiences, the established self. Due to his age and his understanding of a heart attack he did not believe it could be cardiac, but soon realised his symptoms were not normal and were serious. When he got outside Bill's pain worsened, he felt sick and clammy. The first aider on the site took one look at him and called an ambulance. He was taken to the nearest hospital where they did an ECG (Electrocardiogram) and rushed him straight to theatre where they inserted a stent into one of his coronary arteries. The whole process had taken less than an hour and his wife arrived after the procedure was over and he was on the ward. He spent 5 days in hospital, which was difficult as his wife did not drive and had to rely on family and friends to see him. Their youngest daughter was only 9 months old and had to be cared for by family so his wife could visit him.

Bill found the experience a shock, particularly as he was so young and was scared of what might happen to him in the future and the impact on his family. "I was scared it could happen again, I was scared to do anything and wasn't sure what I was going to do" he said during the interview. He felt threatened by the event, felt it was a de-stabilising and disruptive life threatening situation. As a casual labourer he does not receive any pay when he is off work so the financial implications of his myocardial infarction caused him to be frightened about looking after the family. One of the first things he did on discharge from hospital was to go and try and sort out some benefits from the social services, but this entailed loads of form filling that he found difficult. He said that coming out of hospital and having to sort out the money side of life was hard as he did not feel up to it physically or mentally. He worried about going back to work as the job requires fit men and is very heavy. Although his brother is his manager he would not be able to make allowances for him if he was not fit to work.

The support theme was an important part of Bill's ability towards the adjusted self. He has a good family support and has an extended family network. His wife Tracey has been a great support and is cooking healthy meals for him. He knows he is overweight so Tracey is giving him smaller plates with pasta and salad. He said "It has been hard on Tracey with the kids and getting through to Sunderland every day to visit". He thought the support from health professionals had been good but because the whole event happened so fast "I found it hard to take in all that was happening to me". He is seeing the practice nurse at the GP practice to try and give up smoking but is finding this a

challenge. Tracey does not smoke and is trying to encourage him to stop. The person he shares a van with at work smokes in the van so he has found this particularly hard and he sometimes gives in to temptation and has a cigarette with him. He has tried talking to his colleague but he does not listen to him and continues to smoke, "He won't listen. He doesn't listen to anyone" Bill says. He has returned to work and his brother has managed to put him on light duties for the moment. He could not afford to be off for more than 6 weeks, but is finding it hard as he works all over the country.

Since his cardiac event Bill has enrolled on a GP exercise referral scheme and is using an exercise bicycle at home when he is not away with work. He had been offered cardiac rehabilitation after his cardiac event but had refused this. He said it was too hard for him to get there as he could not drive and he had to return to work as soon as he could for his family. He was concerned that the cardiac rehabilitation programme would be a group of old people and he did not like groups, "there would be old people there and I'm not one for groups, I'm more for the family and we all do things together" he argued. He preferred to be with his family and do activities with them, his brother was trying to persuade him to get back to weight training but this was not recommended following a myocardial infarction. He said he would have considered cardiac rehabilitation if it was offered in the evenings or a one to one session where he would not have felt so self-conscious. He thought that people who attend the group sessions were lonely or on their own, or they liked the group sessions, probably retired people with time on their hands that liked to talk about their problems. Bill talks to his family about his concerns and problems and does not need this outside help. He felt cardiac rehabilitation groups would not meet his health needs and made an informed choice to refuse. He tried to address his risks with the support of others but continued to struggle with smoking cessation.

Bill has been pleased with his care. His only concern was that he has had no cardiology follow-up, despite this been promised at discharge. His GP and practice nurse have been supportive but he feels he needs some help with his weight management. He found the follow up at home by the specialist nursing team good and was grateful for the opportunity to talk to someone about what had happened and why. He felt he had been given enough information and the Heart Manual was particularly helpful, "the follow-up here at home has been good and being able to talk to someone about what has

happened". The most difficult thing for Bill to overcome was his continuing battle with giving up smoking but as he says "I suppose that's down to willpower and me".

Bill's cardiac event will affect him and his family for the rest of his life. He is aware of how his previous behaviours have contributed to the myocardial infarction, and knows what he needs to do to achieve good health in the future. Tracey and his family support him and give him encouragement to achieve his goals, which he is grateful for and he has managed to return to work and sustain the family through this difficult time. The shock experienced by the cardiac event stays in the back of his mind and he is conscious of the possibility of it occurring again, but he does not dwell on this and maintains a positive outlook to life. He is beginning the journey towards the adjusted self, appreciating his family, re-energising his work commitments and re-assertion of his provider role within the family.

#### **6.2.2 Case example two (Clive)**

Clive is a 62 year old man who is unemployed and living in the second poorest electoral ward in Darlington. He was in the army for many years but was retired from this due to post traumatic stress disorder. He has had a number of jobs, including running his own mobile phone retail shop. He has diabetes, arthritis, angina and previously had cardiac surgery in 1999. He has had long standing mental health problems since his retirement from the army culminating in several suicide attempts over the years and is under the care of a community psychiatry team. He lives alone and struggles to look after himself due to his co-morbidities but gets help from a carer once a day. The three main themes (1) support, (2) choices and risks and (3) meeting health needs are all described within this case example.

Clive has had angina for a couple of years and has managed it effectively with medication. On the day of his myocardial infarction he had experienced intermittent chest pain all day that was not responding to his Glyceryl trinitrate spray (GTN), cancelling a meeting he had arranged and ignoring it as best he could. By 2100 hours he knew that the chest pain was different from his usual angina symptoms but he continued to try and ignore the worsening pain. He tried playing one of his Xbox games but was unable to complete more than five minutes on this. The pain became "overwhelming" and he said to a friend who had come to visit that he felt he was having a "heart attack".

He asked his friend to go out and buy him a quarter pounder beef burger, with cheese and fries, which he did, and Clive managed to eat it. He had a long-standing pre-determined way of handling his cardiac condition after many years of maintaining his adjusted self. He chose to ignore symptoms and try and put events to the back of his mind, he described himself as “a stubborn sod, you know what I mean and I have a death wish”.

Clive's friend tried to persuade him to call the ambulance, but he refused because he did not want to go to hospital. He remembers the event saying “ he says why don't you phone the ambulance and I says bugger off theres nothing wrong with us man, and he says but I thought you said you were having a heart attack and I says yes I think I am but I don't want to go into hospital”. He phoned another friend in Scotland and explained how he felt, who persuaded him to call 999. By this time it was 2230 hours and it was only a few minutes before the ambulance arrived.

When he got to hospital Clive had bloods taken and an ECG. They did not transfer him to coronary care until the blood results confirmed he had experienced a myocardial infarction. He says “I waited and the doctor came to see me and I kept asking if I could go home. She took me bloods and came back and said there is a problem, you have had a heart attack so that's when I went upstairs to the chronic care (coronary care)”. He stayed in hospital for five days. He was pleased with the care he received in hospital and understood what was happening as he had been in coronary care before his coronary artery bypass surgery. Whilst in hospital the doctors adjusted his medication and kept him monitored.

When he returned home he was surprised that a community cardiac nurse contacted him and arranged to visit, as when he had cardiac surgery he did not receive any post-operative support, although a district nurse did come and redress his wounds. The cardiac nurse gave him support and advice on how to manage his condition, did his blood pressure and organised the GP to titrate his medication. Clive was grateful for this input and felt the nurse gave him more information than he had received in hospital. In coronary care they did not explain what was happening and no-one had told him about the damage to his left ventricle but the community cardiac nurse explained what had happened to his heart. He was not critical of the care he received in hospital but the

community cardiac nurse had completed the process for him. The professional support he received had helped him through his de-stabilising and disruptive life-threatening situation, "I was quite surprised when I got a phone call from the nurse cos I didn't know he was coming. I got the most information off him".

Clive complained that he did not have a good support network saying "I used to have a lot of friends but when I stopped playing golf they just disappeared .....I only have a couple of friends and I rarely see people", and socially Clive feels isolated. He has a couple of close friends but rarely sees people, keeping in contact only by phone with them. His main support is his community psychiatric nurse who sees him once a month. His family are not supportive. One brother did come and see him after he came out of hospital and let other family members know what was happening but none of them contacted him. He has a family history of heart disease with one brother having had coronary artery bypass grafts and one an aortic valve replacement.

Clive could not remember if he had been offered a cardiac rehabilitation programme by the community cardiac nurse. He did not know if he would have wanted to go to a programme as he had done it before following his cardiac surgery. His other co-morbidities also affected his ability to exercise as he had surgery on his spine and problems with his legs. He did not feel that the cardiac rehabilitation programme would have met his needs saying "the problem I have got with that (cardiac rehabilitation) is I've had surgery on me spine and problems with me legs etc so I think I'd have stayed away from that anyway cos I'd have generated more pain in me legs".

Clive admits he struggles with looking after himself in his ground floor flat. He has an unhealthy diet, but the cardiac event has not affected his eating habits. He continues to smoke cigarettes, although he had previously stopped for 7 years following his cardiac surgery and knows he can stop again if he wanted to. He has made some lifestyle choices in an informed way, such as continuing to smoke, but his poor diet is dictated by his carer who cooks for him, "my diet is horrendous". He confessed that he was not bothered about living and only gets his medication once a week as he is considered a high risk for self-harm. He has tried to commit suicide eight times over the years, the last time was two years ago. Although he does not think the heart condition is related to this he admits that he would not have gone into hospital if his friend had not persuaded him

saying “I don’t think I’d have gone to hospital if me friend hadn’t said come on, come on, come on”. He argues that he would have just sat in the chair and dismissed it as angina.

The next stage in Clive’s recovery is he has to have further investigations into the extent of the damage to his coronary arteries (angiogram) and his left ventricle (echocardiogram). He is finding his angina difficult to control and finds the GTN spray does not always hit his mouth when he tries to administer it, due to the arthritis in his hands. He gets angina on minimal exertion and takes his GTN several times a day.

Clive talked at length about his post traumatic stress disorder (PTSD). This began in the 1970s after he had been serving in Northern Ireland with the army. It has affected every aspect of his life. He was unable to make a success of his business due to the mental health problems he had, socially it has affected his life and he could not sustain a relationship. His suicidal thoughts affect his decision making and he said “that is why when I had me heart attack I just thought so what, if I go into hospital and I wake up dead then I’m dead aren’t I, no feeling, you don’t feel it”.

Clive changed his interpretation of what was happening during his interview. Firstly he said he recognised his myocardial infarction as a “heart attack”, then he thought it was just “angina” and he did not want to go into hospital, then he changes to a wish to go into hospital to die. For him the challenges of heart disease and mental health issues affect his life. He argues that he has no wish to live, yet he continues to take the cardiac medication and considers his smoking habit. By delaying the call for an ambulance the day he had the myocardial infarction this has worsened his long term outcome as the long wait caused irreversible damage to his left ventricle and he has been left with heart failure. He was embedded in the threatened self stage of his recovery, partly due to his mental health issues and isolation. He has not yet made the transition towards the adjusted self and has not adjusted after the cardiac event to re-appreciate, re-energise or re-assert himself.

### **6.2.3 Case example three (Doreen)**

Doreen is 54 years old and lives in a ground floor flat with her partner and three children in the poorest electoral ward in Darlington. Doreen has never worked and her partner gave up a labouring job to care for her and the family 5 years ago. She has diabetes, asthma and uses a mobility scooter due to arthritis. She has never had a cardiac illness

but has a family history of strokes and heart disease. Doreen's story includes the three main themes (1) support, (2) choices and risks and (3) meeting health needs.

The evening of the heart attack Doreen was at the local bingo with a friend. After the first session of bingo, during the interval she went to get a drink of water and felt her arms become heavy. She could not lift her arms and realised it was not her arthritis or diabetes causing it she says "I've never had anything like this before like as a side effect of the diabetes or anything and I got myself back to the table and the pains started in the chest". She rang her partner to come and pick her up as she was feeling increasingly unwell. The bingo manager and a first aider came to see if she was alright and soon she was surrounded by staff and customers. She was well known in the bingo hall and all the staff knew she was a diabetic but she explained that this feeling was not due to that and was sure something else was happening saying "I think we can go one better tonight lasses". They offered to call an ambulance but she explained her partner was on his way and sat and waited.

Doreen's partner took her straight to accident and emergency at the local district hospital and she was put into a cubicle. They put her on a cardiac monitor and then left her for 2 hours in the side room with only her partner, "five minutes later everyone deserted me, half eight came, nothing, nine o'clock came, nothing, ten o'clock came, nothing. She said no nurses or doctors came in to check on her and see if she still had pain and she assumed it was not as serious as she had suspected. She felt her blood sugars were rising and she was starting to get agitated, saying to her partner that she would leave soon if no-one came. After a further 15 minutes no-one had come so she packed up her belongings and started to leave saying "I didn't have my insulin in my bag or anything, I could feel meself getting really bad and I knew it was my diabetes. At a quarter to eleven I said that's it and when I walked out theres five of them at the desk sat with their feet up drinking coffee", so she explained that she was leaving. They argued that the doctor was busy but by this moment she was angry with them and left the hospital. That night she took extra insulin to control her diabetes and she continued to have chest pain all night and took morphine tablets to try and relieve it.

At 8 o'clock she rang her GP practice and made an urgent appointment, by 8.30 am she was seeing her GP. He thought she had probably had a severe episode of bronchitis

and gave her a prescription for antibiotics. On the same evening her GP rang her and raised concerns that the symptoms may be cardiac, advising an ECG and some blood tests some time during the week. Four days later Doreen had the tests done in the GP practice, with the ECG showing cardiac changes. By this time Doreen had no chest pain symptoms and felt much better. The GP rang with the results later that day and explained that she had experienced a myocardial infarction and prescribed cardiac medications for her.

Doreen described her health history in depth. She had suffered ill health since she was three years old. When she was fifteen years old she got bronchitis and pleurisy which resulted, according to her memory in a “heart attack”. The doctors did not think she would survive and “even filled in me death certificate out just ready to put the time and signature on the bottom”. She recovered but had a further serious health problem with “blood poisoning” soon after.

Doreen was shocked when she discovered she had experienced a myocardial infarction but is grateful for the support of her family. She was restricted in the exercises she was able to do after the cardiac event due to her other health problems but tried to adapt them to suit her situation. She does not drink alcohol but was a cigarette smoker before the cardiac event. Her and her partner have managed to give up with the help of medication and will power, “the only thing I have been able to do for meself”. She has tried on several occasions to try and stop smoking, particularly when she had her children but had never been able to do it. She does not believe it will necessarily help her live longer but feels it is worth a gamble, saying “nobody can say you are going to live longer you just don’t know, you don’t know whats in store for you but you can’t sit around and say well I’m not going down town because the pressure its going to cause”.

Doreen loves her family and wants “quality time” with them and to enjoy her life. Her partner “gets me through everything”. Her diet was already good due to the diabetes and she has always been careful about getting an even amount of starches, sugars and fats. She has been having problems sleeping since her cardiac event. She has always been a good sleeper but is restless now and only sleeps until 1am and then wanders around the flat. Doreen helps care for her father, taking him shopping and cooking for him. When



they go into town she is restricted with her mobility so her father hangs onto her electric scooter and that is how they manage to shop.

Doreen does not feel that she has had any support from the hospital doctors and nurses. She believes they have done nothing for her. She was visited at home by a community cardiac nurse who visited twice and said that she would come back to see her after she had undergone an angiogram but she never came back. She argues that no-one has informed her GP about what was happening and she had to do this herself. Doreen found the heart manual useful but was unable to read it due to poor eyesight. Her partner read it to her and together they learnt about how to manage her condition. She liked the way it was divided into stages of recovery. It explained to her what a heart attack was, how it can affect you, not just rehabilitation but the way you are feeling. The questionnaires throughout the manual were helpful so that you could fill them in about how you are coping. It was good for her as she could look at the manual at her own speed, together with her partner, saying "most of everything I learnt was from the manual".

Doreen was offered cardiac rehabilitation at the hospital and attended once. The room where the group met was small, with chairs all around and other patients were doing their blood pressure measurements on digital machines. She was late because her partner had problems parking and by the time she got there the session was nearly over. She was aware that all the other patients were much older than her but she seemed less fit and well, this made her self-conscious "everyone else in there is about one hundred and forty years old". She only attended one session and never went back so missed much of the information she would have received as part of the programme. The timing of the sessions did not suit her family life as it was at the same time as the children were coming in from school, although she would have persisted with it if she felt it would have been of any benefit. Part of the session was in a gym where patients did exercises and took their pulses, followed by a cup of tea and discussion. She felt she had better things to do with her life and felt restricted by her arthritis during the exercise component.

Doreen is reluctant to take the cardiac medication she has been given due to side effects, "they've got me on medication to keep my BP low but I already suffer a low BP and you feel like your toes have been chopped off and all drained so get rid of it, I don't

need it, I don't want it (betablocker). Slightest ooze or scratch and I'm pouring blood they have got me on these ones so get rid, I don't need it, I don't want it (aspirin). I finally get rid of them". She said that no-one had sat down and discussed her medication and why she was taking it. She argues that after her angiogram no-one explained what the blockages were and what this meant for her future management.

Doreen was very angry about her cardiac event journey and felt she was not given the support she needed at all the stages of her recovery. Her journey from established self, threatened self towards adjusted self has been helped by the support of her family. She has been able to make significant health choices and changes, by giving up smoking, and looks to the future with her family. Her concordance with medication is a long term issue and she will make choices about taking it based on her experience and knowledge.

### **6.3 Summary**

The three case examples highlight the three main themes found in the previous chapter; (1) support, (2) choices and risks and (3) meeting health needs. Exploring the themes within the context of the established self, threatened self and towards the adjusted self allows the researcher to further understand the participants' journeys from cardiac event to returning to normal living. All the participants had the same diagnosis but with different experiences throughout their cardiac journey. The participants showed that they had, through their cardiac health journey undergone physical, emotional, psychological and social issues before they had been able to come to terms with their diagnosis and the management of their future condition. In the next chapter the findings will be discussed and their implications for practice in developing cardiac services.

## CHAPTER 7 - DISCUSSION

### 7.1 Introduction

In the findings chapters the participants gave their experiences following their cardiac event. The interviews and the case examples produced in-depth, rich data that was analysed and themes emerged. In this chapter the discussion will focus on developing the study further by exploring the 'established self', the 'threatened self' and 'working towards the established self' to inform practice for the future.

Previously there has been very little qualitative work into socio-economic barriers to people accessing cardiac rehabilitation. There is limited research into peoples' experiences with phase three cardiac rehabilitation that have a diagnosis of angina or have undergone revascularisation, especially in the area of socio-economic deprivation. The understanding of the complex needs and social expectations of socially deprived patients needs further study in relation to educational levels and appropriateness of programmes for them.

The new Government white paper, *Equity and Excellence: Liberating the NHS* (2010) calls for a need to put patients first. It argues that we need to give patients a greater choice with shared decision-making in their care that reflects the needs of each individual whatever their need or background. This study shows the need to address this issue with the unheard patient, rather than focus on those who use services. Despite encouragement at Government level to involve patients in their care and service development there is little evidence of this occurring in those who do not access services, particularly the socially deprived. This group of vulnerable patients are the 'unheard' voice of the health service. Using a Heideggerian phenomenological approach to the study enables the participants' journeys to be explored in depth.

This chapter discusses the issues raised in the study and explores them in depth in relation to the research question with recommendations for future service provision in cardiac rehabilitation and the long term management of chronic illnesses. The study will be of interest to all health providers, highlighting the importance of the unheard patient within service development and provision, encouraging further research to explore other

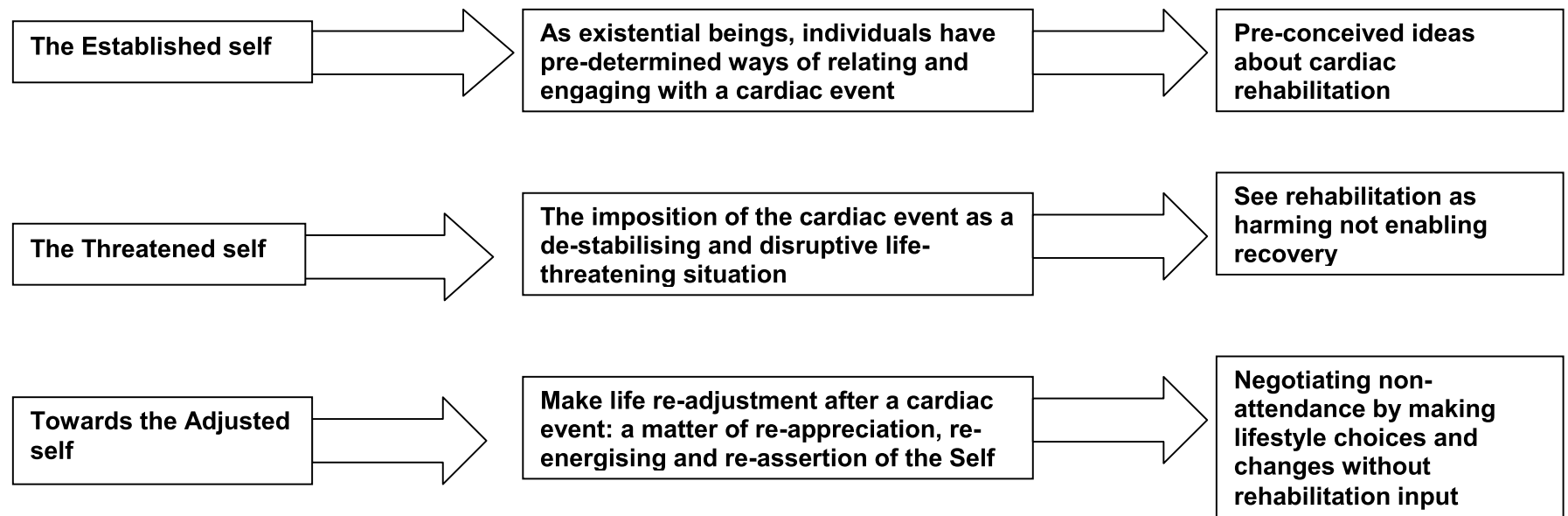
ways of working and involving those who are at most risk. Involving these patients in their care and service provision is a challenge as they are a hard to reach group. Their beliefs and perceptions in this study can be considered as valuable not only to researchers but to health care professionals.

## **7.2 The 'Established self', the 'Threatened self' and 'Working towards the established self'.**

This study has used a Heideggerian phenomenological approach as a means to explore the issues in an illuminative and insightful way (Anderson 1991; Heidegger 1966). This approach was chosen and adapted to enable the participants to give their story through their health journey, and the researcher the data to explore what meanings can be gleaned from the analysis. The journey the participants encountered has no previous blueprint, so the study needed to adapt the Heideggerian ideas to provide a greater insight into why people from lower socioeconomic backgrounds do not access cardiac rehabilitation.

The analysis found that three emergent elements of phenomenology could be identified to describe the participants' journeys. These were (1) established self, (2) threatened self and (3) working towards the adjusted self. The 'established self' was how the participants related and engaged with their cardiac event, the 'threatened self' was how the cardiac event had destabilised and disrupted their lives and 'working towards the adjusted self' was making life adjustments after the event (see Fig.4).

**Fig.4 The 'Established self', 'Threatened self' and 'Adjusted self' journey based on the Heideggerian phenomenological approach.**



### **7.2.1 'The Established self'**

Prior to their cardiac event participants had some pre-understanding of cardiac disease and its effect on everyday life. These understandings, or beliefs will have been based on family or friend experiences, the media or on their own previous illness experiences (Cooper et al 1999). According to Heidegger (1962) individuals have a tendency to engage in life events within a set of pre-understandings by virtue of their existential being in an existing world. This is a useful concept when looking at cardiac rehabilitation. The pre-understanding the person has about the potential benefits or harm of cardiac rehabilitation contributes to their decision not to attend. Health professionals provide verbal and written information about how the programmes are facilitated but the patients' gain more 'credible' information from friends, family and the media.

The participants' pre-understanding of a cardiac event is an important issue in their health journey from diagnosis to the present time. The experiences of the participants can be related back to the Health Belief Model (Hochbaum 1958) in how they understood what was happening to them. The perceived seriousness and their perceived susceptibility to the risks involved from the event affected their coping with the diagnosis. The perceived benefits and barriers to attending a cardiac rehabilitation programme were strongly outlined by them, as was their self-negotiation about lifestyle changes.

Denial was a factor in some of the participants' coping strategies. Their perception of the event was influenced by what their previous experiences were, with some convincing themselves that the event was not cardiac but indigestion or their arthritis, trying to normalise their symptoms. This finding supports previous research by Richards et al (2002), who explored peoples' beliefs of chest pain in socially deprived areas, finding that individuals in socially deprived areas were more likely to normalise their symptoms than those from more affluent areas.

Normalising also has an effect on a persons' willingness to attend phase three cardiac rehabilitation. In trying to return to normal, participants felt that rehabilitation would hinder this recovery, possibly making their illness worse. The participants in this study did not display guilt for over-using services, or guilt about seeing their GP or practice nurse, but did blame their previous lifestyles for developing heart disease. Accessing

cardiac rehabilitation due to a fear of blame from the health professionals was not an issue for the participants.

How participants perceived their illness was an important factor in this study. According to Leventhal et al (1984) in their illness perception model, individuals evaluate their health threats by developing their own ideas about what is happening to them. These deep rooted beliefs affect a persons' decision making about their health management. The participants negotiated lifestyle management according to previous experiences, continuing to practice risky lifestyles if they felt that to do so would cause them less stress or ill health. They continued to smoke, eat unhealthy diets or not increase physical activity, as they felt this would cause their illness to worsen and their symptoms to increase. They had preconceived ideas about the benefit of cardiac rehabilitation and the benefit of attending structured programmes. They all believed that the rehabilitation programme would be detrimental to their well-being and cause them to feel less well. They thought that only older people, who wanted to 'languish in the sick role' attended phase three cardiac rehabilitation sessions.

The relevance of phase three cardiac rehabilitation to the participants at this point of their journey did not seem relevant to them or appropriate to their well-being, hence this study was developed. These findings were also found in the work of Cornwell (1984) in her study of families in the east end of London. Despite input from health professionals within the hospital and in the community, misconceptions about symptoms and the benefits of lifestyle changes existed.

The participants had all received verbal and written information about their cardiac condition in the form of the 'Angina Plan' (Lewin 1999), or the 'Heart Manual' (Lewin 1996). They had found this information useful but had only taken the health messages they contained in fragments to suit their own health beliefs. Lewin (1999) argues that misconceptions should be addressed early in the patients' cardiac journey to prevent malformation of perceptions that can influence a persons coping strategies for the future. By reading the information given the participants did not disengage themselves from their misconceptions, merely re-asserted them. There is a need for information to be re-styled to sell cardiac rehabilitation as a positive step in their recovery.

Illness beliefs provide an insight into a persons understanding and concern about their health. The study highlighted the perceptions of the event by the participants. Clark et al (1998) described the illness perception model, where individuals evaluate their health threats by developing coping and adjustment strategies through their health perceptions. Many of these perceptions have been established long before the event through the media and peer experiences. The development of phase three cardiac rehabilitation programmes have not addressed the illness perception models, although cognitive-behavioural approaches have been used in the development of written material such as the Heart Manual or Angina Plan.

Establishing persons' perceptions at the beginning of their health journey could enable health professionals in delivery of relevant care to suit their needs. This acquired knowledge of a cardiac event and the symptoms did not help all the participants, as they did not all experience a classic cardiac event as understood from media depiction or peer experience. Heaviness of the arms, indigestion-like symptoms or breathlessness masked the true nature of the initial event. Once accepting their cardiac diagnosis from health professionals, all the participants believed the medical diagnosis they were given, all understood what had happened to them, their long term management and lifestyle issues.

### **7.2.2 'The Threatened self'**

The life-threatening potential of the event, its unpredictability and risk of potential disability results in destabilising the foundation of the participants' established selves. The cardiac event was perceived by the participants as a stressful life situation. It triggered the sense of personal threat to their functional abilities as individuals. This was made clear by participants within the interviews. These reactions were found in other studies (Winters 1999; Jackson et al 2000), where individuals found their cardiac events very stressful through loss of personal control over their situation. The event also caused disruption to the participants' lives with loss of personal independence and freedom to carry on their daily living. The event caused them to re-evaluate purpose and meaning in their personal existence, in order to restore order and stability to their lives.

Fear and shock about the cardiac event and diagnosis had a significant impact on the participants. This was not affected by age, the fear of a re-event was found in all the



participants. All the participants had other issues to deal with aside from their cardiac event. Some participants had a fear of hospitals that affected their willingness to stay in and be treated, with three discharging themselves. One participant discharged himself following his diagnosis, only to be readmitted four times before he accepted medical help. The fear and shock they experienced threatened control over their lives, causing disruption and instability.

The 'Threatened self' became a cycle as the cardiac event affected the participants, then their family and carers, who also felt the impact of the threat to their normal lives, and back to the participants who worried about their loved ones. Participants were unable to fulfil responsibilities they had within the family. These included caring for a dying wife, financial responsibilities, or not wanting to be a burden to families with their own commitments.

Participants with no family or friends felt isolated. One participant lived with his wife but experienced isolation as he did not want to talk about his cardiac event and how he felt. He felt he could not discuss his issues with anyone. One participant had a fatalistic approach to life and that what happened to him was meant to be. Long-standing mental health issues was a factor in those participants who felt isolation, with one trying to commit suicide eight times. These mental health problems were not due to their cardiac event but were exaggerated following their cardiac event. Their experiences highlighted their loss of control and stability within their fragile existence.

Health care providers need to intervene in the cardiac cycle to provide holistic care for patients and their families. Reducing the amount of time a person is in hospital, providing investigations as an out-patient and effective community care would contribute to reducing the effect of the cycle. Benefit advice at an early stage would alleviate some of the practical financial concerns that participants experienced. Multi-agency working between mental health and primary care health professionals to address the physical and mental issues experienced needs more resources. The benefit of cardiac rehabilitation sessions were perceived by the participants as not relevant to them as they tried to regain control in isolation, with little or no support.

The presence of grief and loss were important factors in the participants 'threatened self' experiences. A diagnosis of a life threatening disease can result in an individual feeling similar feelings as those of a bereaved person. All the participants expressed some elements of loss and grief from diagnosis onwards and the fear of a re-event. This is an important factor in individuals not attending cardiac rehabilitation. The service is offered 2-4 weeks following a cardiac event and this time is not adjusted to the needs of the individuals' coping timeline. Some people can adjust to their diagnosis quickly and are ready to contribute to their return to normal living, whilst others take longer. Offering a person cardiac rehabilitation before they are able to psychologically cope with their diagnosis could be detrimental to their well-being.

Previous studies into cardiac rehabilitation have not focused on grief and loss as a concept for people not accessing services, but research exists that it is a factor in the health beliefs of people who have had a myocardial infarction. The research outlined below can be linked to all people with heart disease, not just those who have had a heart attack. This is an important concept when looking at why people do not access cardiac rehabilitation services, as the existence of feelings of grief and loss could be influential in a person's decision to not attend. It could be a factor in the timing of offering a person a cardiac rehabilitation programme and the design of services for these individuals.

The relationship between depression and increased mortality has led to an increased concern about a patient's psychological well-being after a myocardial infarction (Jones and West 1995, Thomas 1995; Moser and Dracup 1995; Crowe et al 1996). Patients can experience feelings of loss (Robinson and McKenna 1998), often recalling a sense of numbness (Holloway et al 2000; Owens et al 2001) similar to that experienced by people with post-traumatic stress. Central to the psychological impact of a myocardial infarction is the feeling of loss and grief.

Freud (1917) is credited with the initial ideas that helped shape the development of the phases of loss. He outlined the relationship between depression and grief in his classic text 'Mourning and Melancholia' in 1917. The thoughts in this paper underpin psychoanalytic theory of depression, and provide the basis for current theories of grief. Freud argues that people become attached to others who are important for the satisfaction of their needs and to whom emotional expression is directed (cathexis). He

believes a bereaved individual needs to accept the reality of loss so that emotional energy can be released and redirected. The process of withdrawing energy from the lost object is called 'grief work' (decathexis). He regarded this intra-psychic processing as essential to the breaking of relationship bonds with the loss, to allow reinvestment of emotional energy and the formation of new relationships with others.

Bowlby (1981) argues that people go through a number of stages of grief – numbness, yearning and searching, disorganisation and despair before reaching a stage of reorganisation. He argues that people may fluctuate between phases, although over time people will move through all the phases. He emphasised the emotional aspects of loss and the need to work through the loss to allow the person to let go.

One of the most influential models of grief is that of Kubler-Ross (1969). Her grief cycle is a roller-coaster ride of activity and passivity as the person goes through their grief journey. The first stage is shock, where a person feels initial paralysis at hearing the bad news. The second is denial, where a person tries to avoid the loss. The third stage is anger and frustration with stage four focusing on bargaining a way out of the situation. The final two stages, testing and acceptance seek realistic solutions and finally find a way forward. A common problem is for a person to get stuck in a phase, unable to move on, leading to un-resolution and acceptance.

Loss is a negative experience that invokes varying degrees of fear, anxiety or depression in patients. For people who have had a myocardial infarction, a multiple-loss experience happens in their lives from unemployment, loss of self esteem (Jones and West 1995), difficulties in their relationships and loss of control, feelings of hostility and anger (Moser and Dracup 1995). For many, they fear another heart attack and possible death (Goble and Worcester 1999). Worden (1991) described this as 'anticipatory grief', a role reversal experienced by relatives of dying individuals. This model applies to people who have heart disease, living in fear of a further event or death. He suggests that grief is a process, not a state and that people need to work through their emotions to achieve complete adjustment. According to Payne (2004) the most influential perspective on loss has been to focus on the experience of distressing emotions and the accompanying cognitions and behaviours.

Studies into grief can be related back to this study and are relevant to the feelings participants expressed. Lindemann (1944) suggests that acute grief is not a medical or psychiatric disorder but a normal reaction to a distressing situation. It may happen immediately after a crisis or may be delayed. He describes morbid grief reactions that represent distortions of normal grief. A person may delay their reaction so that they can fulfil some important task, or may even delay it for years. Some people may experience distorted reactions where they may feel irritation, euphoria, hostility or over generosity.

Bonanno (2004) examined loss in the context of trauma and human resilience. He suggests that many people are exposed to loss or traumatic events at some point in their lives and yet manage to cope with the loss. Most people are exposed to at least one violent or life-threatening event during their life time (Ozer et al 2003). Everyone copes with these events in different ways; some have extreme, acute stress whilst others suffer less intensely and over a shorter time. Some people seem to recover quickly but then begin to experience health or social problems later on from the loss. Resilience to loss and trauma is the ability of a person who is exposed to an isolated and potentially disruptive event to maintain a stable, healthy level of psychological and physical functioning. There are a number of types of pathways of resilience to loss and trauma.

The personality of 'hardiness' (Kobasa et al 1982) helps to buffer exposure to extreme stress. There are three dimensions to this; being committed to finding meaningful purpose to life, the belief that a person can influence their surroundings and the outcome of events, and the belief that a person can learn and grow from both positive and negative life experiences. Another pathway is self enhancement (Greenwald 1980, Taylor and Brown 1988), which is adaptive and promotes well-being. People who are self- enhancers tend to have an active social network.

Resilience to loss and trauma has also been found in people who are 'repressive copers' (Weinberger et al 1979). These people tend to avoid unpleasant thoughts, emotions and memories. In contrast to hardiness and self enhancement which appear to operate on a level of cognitive processes, repressive coping seems to function through emotion-focused mechanisms, such as emotional dissociation. One of the ways repressors and others show resilience and cope well with loss or trauma is through positive emotion and laughter (Bonanno et al 2003). Previously this was thought to be unhealthy denial

(Bowlby 1980), but more recently research has shown that positive emotions can reduce levels of distress by quieting or undoing negative emotion (Fredrickson and Levenson 1998, Tugade and Fredrickson 2004)). Bereaved individuals who exhibited genuine laughs and smiles when speaking about their recent loss had better adjustment over several years of bereavement (Bonanno and Keltner 1997).

A person who has had a cardiac event may experience loss, grief and trauma. Their coping strategies at the beginning of their recovery may affect the long-term outcome. People with a good social network and support will be more likely to participate in cardiac rehabilitation than those who have not been able to go through the stages of grief, accept their diagnosis and future, and move on in a positive way. The research on grief and loss shows the relationship between bereavement and loss, not just from the death of a loved one, but also the diagnosis of a potentially life threatening disease and how a person copes with that in the short, medium and long term. This theoretical base will have a significant influence in the analysis of patients post cardiac event experiences, and their reluctance to undertake phase three cardiac rehabilitation.

Loss is a negative experience for people following a cardiac event, with people experiencing multiple-loss in their lives from unemployment, low self esteem, relationship problems, loss of control, hostility and anger. There is also the fear that they may experience another cardiac event or worse, death. All the participants expressed shock at their diagnosis, anger and frustration at themselves or others, with many bargaining their lifestyle changes to cope with the illness. Participants worried about being able to function as they did before the event, the pressures on their families, their isolation and their mental health.

There are a number of resilience pathways to resist the effects of loss and trauma that can be adopted. 'Hardiness' (Kobasa et al 1982) allows an individual commitment to finding a purpose to life, belief they can influence their surroundings and outcomes, belief they can learn from positive and negative experiences, self-enhancement. Of the participants there are examples of each of these dimensions. One participant believed her family were the most important influence on making a full recovery and leading a normal life. One changed his life, increasing his physical activity and returning to work, able to influence his surroundings and outcomes in a decisive way. Another participant

had been very ill prior to his heart surgery and post operatively he was able to rebuild his life, learning from the negative and positive experiences that his life was full and fulfilling. Others feel better since their cardiac event and made healthy changes to their lifestyle, returning to self-enhancement.

Health professionals providing cardiac rehabilitation services can incorporate the concept of 'hardiness' into their programmes. By enabling a person to appreciate they still have a purpose in their life, and that by having a cardiac event they have not lost their role within the family, work and society. This can be addressed whilst a person is in hospital, revisited when they get home and supported throughout the cardiac journey.

The participants' health journey stories support the previous research into loss and grief. They feared a re-occurrence of their cardiac event and struggled to come to terms with the diagnosis. This supports the transition from 'threatened self' to their re-adjustment to normal life 'towards the adjusted self'. Participants who showed resilience to loss are more likely to be 'recessive copers' (Weinberger et al 1979). Rather than face up to the loss or trauma these individuals avoided unpleasant thoughts, emotions or memories and carried on as if nothing has happened. One participant wanted to ignore what had occurred, return to work and not let the illness take over his life. Although this could be perceived as an unhealthy denial, it has been shown that people who exhibit this reaction can have a positive affect on their emotions and future prognosis (Tugade and Fredrickson 2004). By ignoring their cardiac event they are able to regain their normal life back. There are issues with this group of individuals around concordance with therapy and treatment.

The participants all experienced the threatened self concept throughout their cardiac journey. Their fear and shock at the diagnosis affected both themselves and their families. The coping strategies that participants adopted throughout this stage of their journey varied from resilience to acceptance. Health professionals can learn from the participants in this study to appreciate their illness perception beliefs and provide ways of empowering them to make lifestyle changes.

### **7.2.3 'Towards the Adjusted Self'**

This study has revealed that participants have had to learn to accept the reality of their situation, internalise its meaning and be consciously aware of the potential impact it might have on their well-being. To engage in life adjustment, all the participants had to realise the importance of their cardiac event, with all of them accepting and coming to terms with what had happened to them. This was despite a fear that another cardiac event could occur or complications from the illness, in the future.

The underlying forces of the 'Being-ness', of long term adjustment represented a set of collective and purposeful decisions that participants made. They negotiated lifestyle changes within the context of their lives, choosing to change all, some or none to enable re-engagement in their previous duties and activities effectively. They had to negotiate the 'threatened self' through their perceptions of what had happened to them, 'towards the adjusted self' of making life adjustments after the cardiac event that would enable them re-assert themselves for the future.

Re-establishing previous roles and responsibilities within their family was an important driver for those participants who had commitments to provide for their wives and children. It aided their personal healing, self-confidence and re-stabilising the family unit. The ability to make informed choices about personal costs and benefits of cardiac rehabilitation was another significant factor for the participants. Learning to live with the illness and personal sense of well-being revealed to be adequate reasons for the participants against attending the programmes.

'Becoming the active self again' is the 'what is' and what it means', or the 'Being-ness' of long term adjustment for the participants in this study. The cardiac event had not only affected the functionality of their hearts, but their entire 'Self'. In this study the 'Self' refers to the totality of an individual striving to become the active 'Self' again in the lived world (Heidegger 1962). Heidegger argues that the fundamental essence and meaning of the 'Self' can only be disclosed through the every day roles and responsibilities and engagements of human beings, within functionally active and interactive settings. The participants have followed a journey through diagnosis to management of their cardiac illness to re-establish themselves through informed choice and decision-making. The

importance of 'Self' is not fully acknowledged by cardiac rehabilitation provision, although health professionals do endeavour to provide tailor-made care for patients.

Cardiac rehabilitation programmes do try to enable patients to reach their full potential and return to their everyday roles and responsibilities but are limited due to resources as to the amount of time each individual can have access to the service. Engaging those who do not attend a structured programme to allow them to become the active 'Self' would require health professionals providing a service that is acceptable to their well-being. This might be a home-based programme, a one-to-one session or an out of hours service. Clinical psychologist input into patient care from the start of the cardiac journey could provide patients with the skills to return to their pre cardiac event 'Self'.

The Illness perception was an important factor in a persons' willingness to access cardiac rehabilitation services. How they perceived the threat to themselves because of the cardiac event on their current management of the disease, and subsequent potential for future events was highlighted (Clark et al 1998; Hampson et al 1990; Lewin 1999).

Leventhal and Nerenz (1985) developed a self regulation model that argues that a person looks for causes or reasons for their illness so that they can understand, predict and control the perceived threat that develops from it. This study supports this model, as eight of the ten participants had clear perceptions of their cardiac event, with some accepting it and others denying what was occurring. The participants generally had a good understanding of what was happening. How these participants reacted differed in their response with some seeking help immediately, whilst others delayed.

Interestingly participants who understood the seriousness of their cardiac event and the need for medical intervention did not want to stay in hospital or accept their diagnosis. The self-regulation model describes five key dimensions of (1) identity; (2) cause; (3) timeline; (4) consequences and (5) cure or control. All the participants were able to identify their symptoms, they described what they perceived as the cause of the event, all understood that the diagnosis of heart disease was a long term condition that could worsen or improve and they were able to perceive the consequences on their lives, although some chose not to accept these and make changes to their lifestyle. The cure or control aspect of the model was the most challenging for the participants as they



came to terms with their illness. The processes a participant regained control was varied with some making lifestyle changes and others choosing to ignore the event. The degree of lifestyle changes was different amongst the group with some making complete changes to their lives, whilst others chose which changes they could make easily and dismissing other changes that were needed.

The support given to each participant both formally and informally is also an important factor in their return to normal living. Social support via family and friends was found to be a significant factor within the study but none of the participants joined formal support groups. There has been extensive research into the benefits of support groups within the literature (Dalal et al 2004; Petrie et al 1996; Bennett 1993). The participants who had support gained emotional, practical help and positive feedback to enable them to feel worthy and capable from their families. There was no evidence that they made a more effective recovery than those who were isolated. One participant resented the support he received from his family and found it suffocating. Participants felt that they wanted to protect their loved ones from their own fears and worries about the diagnosis and getting back to a normal life was a way forward for them.

Cardiac rehabilitation was not a feature in returning to normal living, it was seen as a possible delay in getting their lives back. This issue was also raised in the 'threatened self' as a negative concept that could harm more than benefit recovery. This is an important factor for participants and reflects their perception of the relevance of cardiac rehabilitation.

The support given to the participants from health professionals was given a mixed reception. Some felt they had been given little or no support, whilst others had been grateful for the input of hospital staff, GPs and community cardiac nurses. They had appreciated the time and care they had received. They felt they had been given all the relevant written information but chose to return to the 'adjusted-self' without cardiac rehabilitation. There is a need to revisit the information given to patients and establish what they understand about what is written or said.

In hospital each participant would have had a number of visits from the cardiac rehabilitation team based there. None of the participants mentioned visits from the

cardiac rehabilitation team, yet they were all discharged with the relevant written material that had been provided by the rehabilitation nurses. This could be that they thought they were part of the coronary care or ward staff, or did not remember their input in the information giving prior to their diagnosis. Most referrals from secondary or tertiary care to the community are generated by these teams and their visits to the participants documented in their notes. They all remembered the health professionals in accident and emergency, coronary care or theatre. They remembered the technical support of electrocardiograms, angiograms and echocardiograms.

Cardiac rehabilitation nursing may be seen as a necessary step in their treatment, and so the value of these teams was not recognised. The cardiac rehabilitation teams need to be clear at first meeting the patient what their input is into their care and their roles within the service as a whole. They currently wear the same uniform as nurses on a ward so are indistinguishable. A change of image, clear introductions and clear advice would help patients to appreciate their roles. Offering a patient a visit to the cardiac rehabilitation programme whilst they are in hospital may alleviate some of the concerns about cardiac rehabilitation and make the rehabilitation nurses role more apparent.

The amount of support a participant had did not influence uptake of cardiac rehabilitation, with all the participants making the decision not to attend phase three rehabilitation programmes independently, without much consultation with their families or health professionals. Cardiac rehabilitation had been discussed by health professionals either in hospital or at home but participants did not want to attend. One participant, could not remember being offered the programme. Only one participant had been encouraged by his son to attend, but as his wife was terminally ill he had made an informed choice not to join any programmes.

Despite what changes each individual made they demonstrated a belief that they could control their future health, psychosocial adaption and recovery following a cardiac event. The participants who had a greater perceived control on their psychosocial recovery made a better recovery than those who felt their control had been taken from them.

The severity of the disease did not influence the participants' perceptions of their illness. There was no difference between the genders in the study. This differs from previous

studies (Nau 2005; Kristofferzon et al), who found women to be stronger than men, despite having more severe illness. The women had a greater perceived control on their recovery and were able to adjust to their illness more effectively. The study did find the male participants saw the assumption of paid work as the most important factor to readjustment, but the female participants did not see the need to resume housework as an essential readjustment process. One female participant felt that the cardiac event had released her from household responsibilities, and was happy to delegate this to her partner.

The participants' ability to gain control over their illness was an important factor in the study. Their adjustment to life after their cardiac event involved informed choices 'towards the adjusted self' to achieve 'Being-ness' once again. The provision of cardiac rehabilitation needs to take illness perceptions and health beliefs into account in providing timely services at the point the patient is ready to adjust to their illness and not in the structured phases currently practised. This would give patients the necessary time and resources to re-build their lives effectively, providing them with the skills needed to contribute to their environment.

#### **7.2.4 Perceptions of cardiac rehabilitation towards the 'adjusted self'**

The participants did not attend cardiac rehabilitation as they did not feel it would benefit their return towards the 'adjusted self'. This is the process where an individual makes life adjustments after their cardiac event to re-appreciate, re-energise and re-assert their 'self' within their normal environment.

According to the previous qualitative research studies in this area, individuals from lower socioeconomic backgrounds are less likely to attend a cardiac rehabilitation programme than those from a more affluent area (Tod et al 2002; Wyer et al 2001). Most cardiac rehabilitation programmes are facilitated during the day, with very few in the evening. This is partly historic as in the past individuals who were working were required to take a minimum of 6-12 weeks off work following a cardiac event. In recent years, with the introduction of Primary Percutaneous Coronary Intervention (PPCI) the need to be on sick leave for long periods has reduced. After a PPCI some patients are advised they can return to work within a couple of weeks. As all the participants were from lower socioeconomic backgrounds if they worked it tended to be in low paid manual work. This

employment is usually casual so benefits are an issue for them. Those who did not work either looked after extended family members or were unable to work on health grounds.

Participants did not see the appropriateness or benefit of cardiac rehabilitation to enable them to return to normal living. They perceived cardiac rehabilitation as exercise and did not realise the other components of cardiac rehabilitation such as information, support and advice. Only one participant was positive about cardiac rehabilitation and saw its benefits to others but he had managed to make all the health changes on his own and preferred to continue this. He had returned to work as a labourer. Quality of life was mentioned by most of the participants as an important factor to their well-being. For some their lives had improved and they were able to do more than before their cardiac event, whilst others felt it had a detrimental affect on their lives. Cardiac rehabilitation was for them not an option in their adjustment to their cardiac event and felt that by attending cardiac rehabilitation sessions it would be detrimental to their recovery, preferring to get on with their lives.

Some participants had a better quality of living following their cardiac event and others a worse quality of living. Adjustment to everyday living imposed by the illness was an issue for all the participants. These were made by participants in partnership with family members and health professionals where possible but also alone. All the participants had to face a new time in their life, from taking medication for the first time, making lifestyle changes and undergoing tests and procedures. Shock and surprise at the cardiac event was evident within the study group and has been discussed earlier.

Indignation at the interference of the illness in their lives was shown to be a significant factor within this study, particularly in returning to work and the medicalisation of the event forced onto the participants. There was one participant who felt cautious about physical activity, whilst the others did not see any change. There was some reluctance to the medication regime from one participant, who opening acknowledged that she had stopped some of her medication as she did not like the side effects. There were psychological and physical aspects that affected the participants' daily living. Previous mental health issues had a negative consequence on their ability to make changes in a positive way. One participant only went out of the house to go to the pub, meet people and have a beer. Since the cardiac event he had given up alcohol and also going out, as

his reason for socialising had been removed for him. Another participant with mental health problems increased his cigarette smoking after the cardiac event to cope with the increase in angina he was experiencing. This effect is supported by previous research in this area (Zambroski 2003; Jackson et al 2000).

The process of readjustment involves regaining control and dealing with uncertainties, making sense of situations, seeking independence and sheltering others. This study supports this process, with participants negotiating changes in their lives that they feel will benefit them, rejecting others that they feel would be detrimental to a full recovery.

#### **7.2.5 Limitations of the study and recommendations for future research**

The study was an in-depth, qualitative study based within one town using participants from the five poorest electoral wards. The generality of the study into individuals from lower socioeconomic in other parts of the country may differ according to geographical area and cardiac rehabilitation provision. The location was urban, with cardiac rehabilitation services based centrally. In rural areas of the country access to cardiac rehabilitation services may be dictated by ability to get to venues. Multi-centre research into non-access to cardiac rehabilitation may be useful in the future.

The study was originally designed to use action research as this is an effective approach used in community research. Action research is a process of observation, description, planning, acting, reflecting, evaluating and modifying that can involve patients at all levels (McNiff 2002). Waterman (2001) defines action research as 'a period of inquiry that describes, interprets and explains social situations while executing a change intervention aimed at improvement and involvement. It is problem focused, context specific and future-orientated. The methodology was changed to phenomenology as this allows the participants' journeys and stories to be better heard and explored. Although this has enriched the study, a process of action research would benefit future service development based on the findings of this study.

The researcher wanted to involve patients' carers and family in interviews as there is limited research into this area. None of those participants who had a family or carer wanted their family involved in the study, feeling it was their problem and it was up to

them to talk about it. During the interviews participants did not want anyone in the room apart from one participant who was Polish and had limited English speaking skills.

The study did not examine or measure the educational level of the participants. Some of the participants may have been able to read the written information given, but unable to make an informed choice about attending cardiac rehabilitation as they did not understand the programmes fully. Health professionals often assume that a person has all the information they need if it is in a booklet or fact sheet. Future research into the educational needs of patients from lower socio-economic backgrounds is needed so that information can be given at an appropriate level for the individual.

A comparison qualitative study of patients from lower socio-economic backgrounds and the more affluent areas would enable further in-depth exploration of the perceptions of cardiac patients of their illness and their willingness to attend phase three cardiac rehabilitation programmes. This study has focused on cardiac patients, but further research into other long term conditions and non-access to services would be useful. This would include patients with respiratory, diabetic and peripheral vascular diseases. The 'unheard' patient has rarely been studied in a qualitative way but offer opportunities to understand their illness beliefs and perceptions.

Lastly and most importantly is the need for services to be developed in partnership with the 'unheard' patients. Involving patients in service provision through focus groups, questionnaires and audit have been well established in the NHS. This work needs to continue but extended to those who do not access services that would benefit their long term recovery. Patients from lower socioeconomic groups who do not access services need to be consulted about the services they would like to see and attend. The participants in this research made a number of suggestions about cardiac rehabilitation including evening or weekend sessions, web-based rehabilitation and one to one programmes, but there is more work needed. When a patient refuses cardiac rehabilitation, health professionals have the time and skills to question them on their reasons and report these to the service providers.

### **7.2.6 Recommendations for future service provision**

Government strategies over the last ten years have encouraged an increase in patient involvement in decision making for the development of services and care within the NHS. These initiatives have focused on service users and no organisation has made a strategic effort to ask patients who do not access services why they chose not to take what was offered. This is a gap in service provision and is relevant to this study.

The reasons for individuals not participating in cardiac rehabilitation programmes has already been discussed, but the involvement of these non-service users can help professionals to develop services in the future. Participants suggested one to one rehabilitation sessions, sessions in the evenings for those who did not like groups and weekend sessions for those who worked. Cardiac rehabilitation programmes on the internet so that people could do their programme in the comfort of their home and at their own convenience. Offering evening, weekend or one to one sessions could be considered in partnership with patients to tailor the rehabilitation process to their needs.

More work is needed to explore the 'unheard' patients in how they want cardiac rehabilitation services to develop in the future. Currently the four phases of cardiac rehabilitation are being adapted into seven phases to enable patients to make choices at more stages. This would enable an individual to access the appropriate service for them at a time in their health journey that is right for them. This would allow patients to come to terms with their diagnosis, disease management and psycho-social needs before being offered cardiac rehabilitation. The grief and loss a person feels about their cardiac event can hinder them coming to terms with the diagnosis, so more time and support can be offered to these individuals throughout their health journey. The delivering of the service would need extra input from community cardiac teams to support patients in this transitional period.

Greater understanding by health professionals into illness belief models can assist them in generating information and resources that are relevant to the needs of individuals from lower socioeconomic backgrounds. Information can be written, DVDs or web-based to suit the individual. The use of visual aids such as models can help people to understand what has happened to them and the need for lifestyle changes.

The rehabilitation teams in hospital need to make their roles and responsibilities more clear. Participants did not realise they had been seen by the rehabilitation teams whilst in hospital and this issue needs addressing. Patients need to know who their rehabilitation team is and how to access them if they have any problems they need to discuss. Community cardiac teams need to work closely with their secondary and tertiary care counterparts to ensure the patients have a clear pathway of care.

The development of services does not need to involve more resources, but for health professionals to think outside the area they work. Good interaction between cardiologists, nurses, GPs and other health professionals can work both locally and nationally to develop robust cardiac rehabilitation programmes that benefit the individuals in our society that are at most risk of developing cardiac disease, most at risk of re-admission and most at risk of re-events, the 'unheard' socially deprived.

Health professionals audit services through questionnaires and focus groups. There is a need for more qualitative work to explore patient experiences through their health journeys, particularly with those who are under-represented in the health service. Patients from lower socioeconomic groups are a vulnerable group who are at a higher risk of developing cardiac disease and seeking medical help. More work into primary prevention of heart disease could benefit people at risk of heart disease. Promoting healthy lifestyles through job centres, workplaces, pubs and clubs within a strategic framework should be planned, implemented and evaluated effectively.

### **7.3.2 Summary**

This chapter has explored the Heidegger phenomenological approach to the study and the concepts of the 'established self', 'threatened self' and working towards the 'adjusted self' in relation to the study. The study has shown the participants' beliefs, perception and knowledge in their decision making and coping with their cardiac event. The barriers to accessing phase three cardiac rehabilitation have been explored and examined from the participants' perspective to enlighten health professionals working with cardiac patients. There are a number of lessons that can be learnt from this study and recommendations for future service development and research.



This study provides an insight into barriers that exist in patients participating in cardiac rehabilitation using their experiences. It also provides health professionals with an understanding of how to manage cardiac rehabilitation to incorporate the views of the 'unheard' to produce frameworks for future practice. In the next chapter the researcher viewpoint will be explored as this study has been a journey for her as well as the participants themselves.

## **CHAPTER 8 – THE RESEARCHER’S JOURNEY**

### **8.1 Introduction**

In previous chapters the study has focused on the participants’ experiences through their health journeys since their cardiac event. This chapter will now focus on the researcher’s experiences with the process and the development of the thesis. Reflective practice is an important aspect of academic and practice development so will be a fundamental part of this chapter.

In chapter one the researcher reflected on their practitioner role and how this reflexivity has impacted on clinical practice. In this chapter the researcher will explore researcher’s journey through the Doctorate in Nursing Science (DNSc) programme in relation to this study and their professional development. The exploration will focus on how the Heideggerian phenomenological approach has affected the researcher’s perceptions and beliefs in understanding the health journeys of the participants and ways forward for practice development in cardiac rehabilitation in the future. The chapter is facilitated by a reflective diary that was kept throughout the process.

### **8.2 Background**

When I began the DNSc in 2003 only five universities offered the course. The first DNSc in Europe was established at the University of Ulster in 1995 (Boore 1997). I was due to begin the previous year but the organisation I worked for did not support such a level of study for nurses at the time, so I had to defer until I could negotiate the resources to undertake it. This was a challenging time for me as I argued the case for doctoral nurses in practice and the benefits to the organisation. The main benefits I outlined were (1) nurses educated to the highest level of academic study that could incorporate research with development for personal and professional progression; (2) nurses that can teach and mentor others within the organisation to develop the workforce and (3) nurses that can promote the organisation locally and nationally through their research.

There were eight students commenced the course from all different disciplines of nursing from education, cancer care, sexual health and health visiting. This diversity of skills enabled each of us to share good ideas and practice. Currently three of us are still

progressing through the doctorate programme, an indication of the time and energy needed to undertake such a level of study whilst working full time in demanding roles.

The idea of researching why people from lower socio-economic backgrounds did not access cardiac rehabilitation was one that had interested me prior to commencing the DNSc. As a practitioner working with cardiac rehabilitation I was aware of the need to provide services that had relevance for all patients and was concerned about the 'unheard' communities within my area. I was involved and interested in research and felt the DNSc could provide me with the knowledge and skills framework to take this forward.

The first two years of the DNSc were taught modules relevant to developing the research skills to develop a research proposal and expand our knowledge to undertake the thesis study. The educational philosophy of the course as outlined in the module guide (Carr and Harden 2003) requires the student to work collaboratively on a wide range of issues, using skills of analysis and critical thinking to tackle these. It requires students to be reflective and communicate in an effective way. The philosophy is seen as both complementary and challenging to the existent policy context of professional practice at a local and national level. This period of the course was challenging but I felt supported by the tutors and my fellow students. As we were regularly in University attending lectures it gave us the opportunity to share concerns, issues and solutions to challenges that we all faced. Assignments were designed to enable us to think through our research ideas individually and as a group.

The DNSc student is seen as a reification of a combination of Brookfield's (1986) theory of adult learning and Benner's (1984) notion of the 'expert practitioner'. This is because the course offers the student the use of experience and expertise as a resource for learning, and it facilitates the acquisition of self-directed knowledge to allow them to become more proactive in constructing their understanding of practice.

The course links practice and theory in what Freire (1981) describes as 'praxis', a fundamental relationship between the person, their actions and the world. In this way 'praxis' is a link between reflection (theorising) and action (practice), or as an act of reflexivity constructing and reconstructing the social world (Bloor 1988). The course empowered students through fostering an ethos of community building and action

through which their professional practice can be re-envisioned. Political structures at a micro and macro level were a common theme, encouraging students to develop a vision that could influence policy at a strategic level and develop services within their practice area.

The course provided us with extensive research training and a depth of method study within the taught component. This was defined by Edwards (1997) as partial, local and specific knowledge-claims, the resultant research thesis produced by the student will have an impact on professional and practice issues relevant to their expert area of nursing. The taught components of the course provided a structured, planned and supported approach to doctoral level education, preparing me to explore concepts of practice and practice development, together with research project skills. The course had 3 key themes (1) nursing practice, (2) practice development and (3) research skills that were fundamental to the DNSc and to the student's professional practice. The training needs analysis summarises this in Appendix E.

### **8.3 The practice doctorate versus a conventional PhD**

Once deciding to undertake doctoral level study it became clear to me that I needed to choose the conventional PhD route or the recently developed DNSc. As a clinician I felt the latter offered a more practice based focus that I could develop within my organisation and meet my needs. It is viewed as a viable alternative to the research-focused PhD for those who aim to attain the highest levels of excellence in practice.

Defining a professional doctorate is not easy, Newman (1997) suggests that a PhD is an advanced research degree, preceded by basic undergraduate education in the field, and is intended to prepare scholars who will advance and teach the knowledge of the field. In contrast, a professional doctorate is a practice degree, similar to the Doctor of Medicine degree, and constitutes basic preparation for practice.

The availability of skilled clinicians with advanced practice preparation at the doctoral level will benefit health care in general, as well as the individual patients to whom they provide care. The course enabled me to be well prepared to design, deliver, and direct evidence-based practice; to develop improved practice guidelines; to develop practice

innovations; and to evaluate the effectiveness of complex interventions. From this I would like to be at the forefront of efforts that will improve health care outcomes, patient safety and increase efficiency within my organization and on a personal level. Munding (2005; p.174) predicts that nurses who undertake doctoral studies "will change health care and profoundly improve the nation's image of nursing".

According to Williamson (2008) students undertaking higher-level study tend to be in the middle of their careers, often have families and large-scale financial commitments, making full-time study a near impossibility. This was the case for me, working full time with a family and financial commitments. The first two years of the course were funded by me as the organization was reluctant to support such a level of study. Due to a change in management structure this decision was revoked as the value of doctoral study took on a more acceptable face. The organization began to see the benefits to themselves and the population they served.

Professional doctorates tend to have a research component with great potential for findings to get to practice quicker. Professional Doctorates have been around in the UK since the early 1990's, although some more established doctoral programmes have also been brought under the professional doctorate umbrella. The aim of these programmes is to find novel approaches to integrating professional and academic knowledge. According to the UK Economic & Social Research Council (ESRC 2005), students undertaking a professional doctorate are expected to make a contribution to both theory and practice in their field, and to develop professional practice by making a contribution to (professional) knowledge.

According to Ellis (2003) educators face a challenge in convincing practitioners of the efficacy and value of continuing professional education at doctoral level. She argued that the professional doctorate has a continuum of provision from very prescriptive to minimally prescriptive programmes, with a wide range of attitudes towards it varying from enthusiasm through ambivalence to skepticism. Marion et al (2003) argues that practice doctorates are needed to further clinical leadership within existing complex healthcare by evaluating evidence base for care; delivering the care; setting healthcare policy; leading and managing clinical care and health systems; developing interdisciplinary standards; solving healthcare dilemmas and reducing disparity in healthcare delivery.

The decision to undertake a DNSc rather than the more traditional PhD has enabled me to develop as a researcher and as a practitioner. It provides me with a recognised and valued qualification that will benefit my nursing practice and the organisation I work for. By choosing to take on such a huge challenge I have been able to encourage others to consider that academic-practitioner worth in an ever changing healthcare landscape. As a manager I support team members to undertake the highest level of qualification that they can under my mentorship.

Since commencing the DNSc course all the team I work with have undergone advanced nursing courses such as clinical skills and non-medical prescribing; one nurse has completed her MSc and another is due to start; three of the nurses have completed or are currently on degree courses and our health care support worker has been successful in getting a secondment from the organization for her nurse training. The need for professional development within our team has been influenced by the experience I have had on the DNSc. It has encouraged me and others to take on levels of study that benefit us personally and professionally.

#### **8.4 Phenomenology and the doctorate journey**

There has been much assumption about why people do not access services but I wanted to explore the issue further by understanding the patients' viewpoint. Central to this is to understand the truth as they perceived it in their health journeys. Heidegger's (1962) Dasein explores truth through uncovering beings or entities. Central to the uncovering of entities is the uncoveredness of entities on the basis of disclosedness of the world. The disclosedness of the world, itself not an entity, makes the uncovering and uncoveredness of entities possible. Heidegger argues that these notions are the key to an understanding of the nature and essence of truth.

In understanding the importance of truth it is important to see it in relation to being. Aristotle defined philosophy as the science of truth and as a science that considers beings as beings. In his Dasein, Heidegger truth is an assertion or statement as a derivative mode of interpretation. Statement is a predication, asserted of a subject, uncovering the entity. The location of truth is the statement or judgment, and the essence of truth is the agreement or correspondence of the statement with its 'object',

with what it is about. For example the statement 'I had a heart attack' consists in its agreement or correspondence with the man who has had a heart attack or the state of affairs that this event has caused.

As a researcher I wanted to uncover the entity and according to Heidegger the truth of a statement is its being-uncovering of the entity, or predicative uncovering. The predicative uncovering or truth of statements or judgments is founded in pre-predicative uncovering. World is not an entity, but a web of significant relations which make it possible for entities to manifest as entities. What makes the uncovering of entities possible must be called true in a more primordial sense. Pre-predicative truth is more basic than predicative truth, but truth in the most primordial sense is the disclosedness of world.

As well as disclosedness, uncoveredness is also an important component of truth. Disclosedness makes possible all uncovering, the truth. By existing we are in possession of all truths. Any truths are only true in so far as Dasein is, when there is no Dasein then there will be no truth. This does not make truth subjective in the sense it is up to the individual Dasein whether a statement is true or not. Predicative truth is not the most basic kind of uncovering but it is uncovering. A statement that purports to uncover is determined not by the individual making the statement but by the entity that the statement is about. True statements have universal validity but can only have this character because Dasein can uncover entities in themselves.

The truth or perceived truth is an important concept for me as a researcher. I did not undertake this study to prove participants wrong in their beliefs, but to understand their views about their health journey and their decision-making. I have interpreted the words of participants in what I perceive is a true way, developing themes and recommendations for further cardiac rehabilitation services from the words and stories which have been given.

### **8.5 Doctoral support**

From the beginning of the doctoral process I have been given support via supervision, peers and within my clinical setting. This is fundamental in the success for a student as doing any doctoral study, particularly in the research phase can be a lonely place. There is no other nurse in my organization or within my local district or tertiary hospital who has achieved a DNSc or PhD so I have needed to access support from within the University and from medical clinicians.

#### **8.5.1 Supervision**

I have been given monthly academic supervision with two supervisors since 2003. This has enabled me to access the skills and knowledge from experienced academic supervisors and given me time to address the research ideas, proposal, midpoint review and thesis writing. During these sessions I have made notes in my reflective diary and written up the contents as minutes. My principle supervisor has been with me through the doctoral journey since the beginning, but I have had one change to the supervision team during this time due to relocation of a supervisor. This occurred in 2010 and could have been a hindrance in the process but it proved to be refreshing for both my principle supervisor and myself. I find this time beneficial as the only opportunity to discuss the study in depth and to gain knowledge through the experience and skills of my supervisors.

Lee (2009) discussed research supervision focusing on the processes and issues students and supervisors gave priority in professional doctorates. She argued that research supervision could, or should, embrace critical engagement with issues related to the leadership of research in professional practice; moving beyond research and methodological issues. There are implied differences between professional doctorates and the PhD relating to process, purpose and outcome (Yam 2005; Laing 2000).

It is expected that students need a supervisor or adviser from within their practice setting, to provide insight and support in relation to leading research in practice and to complement the role of their research supervisor. Such complementary supervisory roles within the practice context are given credence in the literature. I was able to do this due to a good working relationship with a cardiologist. He himself has an active research role



and became my clinical mentor at the start of the DNSc process. I am able to discuss clinical implications and service development with him as a clinical insider. This has proved to be an effective partnership. We meet every six weeks for an hour and I make reflective notes from each of these meetings. He provides me with the time to discuss my thoughts about the study and the research process. He is able to make recommendations and has been instrumental in promoting the study within the cardiology arena, locally and nationally.

I developed a project steering group at the end of the taught component of the course and the start of the research component. This enabled me to test ideas and discuss previous research with a group of clinicians, patients and members of the local voluntary sector. The patients were sub-divided into those who had accessed cardiac rehabilitation and those who had not. This group continued until the first few interviews had been completed and was no longer necessary for the research process. They have been kept informed of the study and its progression. The non-medical members provided me with a lay perspective that generated ideas. They enjoyed being part of a research process in its infancy and saw how it could impact on service development. It developed good working relationships with myself and other health professionals, and they helped me to identify possible participants.

#### **8.5.2 Action learning sets**

At the beginning of the research component my fellow students and I began to meet bimonthly for an action learning set. This allowed us to discuss research issues and share solutions to problems, in a reflective way. Action learning recognises that professional development comes from a combination of knowledge, skills and professional growth (Revans 1993). We were able to bring the whole of ourselves to the process and have the freedom to explore as much as we felt comfortable doing, without making firm boundaries between our research work and personal life. It was important for us to share non-work issues as they often had an impact on our ability to develop within the research process. As we met, over time, we were able to build an understanding and trust of each other, helping us to take an active approach to the pressures of life and work.

The action learning process gave us a capacity to equip ourselves to respond effectively to change and ideas. Discussing ideas within the group enabled me to see my research and others from different perspectives. It was useful to think of different ways of approaching the research question and process. It was driven by us, with no need for ground rules or formality. It gave us problem-solving solutions whilst developing ourselves as researchers.

The action learning process is a useful tool in the development of a research study and is increasingly been used within organizations, often under the guise of clinical supervision. It was important for me as I would have felt isolated in the research process without this support. We also keep in regular contact via email and telephone and provide each other with support that would be difficult to access from anyone else.

### **8.6 Personal and practice development**

The reason I commenced the DNSc was to personally develop as an effective researcher and professionally develop within my practice to change, modify or continue service provision with the knowledge and skills I have learnt. At a personal level I have been able to think in a more effective way, using the academic skills at my disposal. The course has given me time to reflect about my role and the role of others within my team.

At a professional level I have been able to inform cardiac rehabilitation practice at a local and National level. I have had the opportunity to present both poster and oral presentations at conferences in England and Europe, promoting my organization and the need for more research in nursing practice. Without the DNSc I would never have had the confidence or opportunity to promote good practice at such a level. I have published articles within nursing and cardiology journals about cardiac rehabilitation and my study. In 2010 I won the British Journal of Cardiology presentation prize for a presentation about this study at the British Association Cardiac Rehabilitation conference in Liverpool, with the abstract published in the journal. This has generated a high profile for myself and my team, and other health professionals from other organisations often ask us to assist them in their service development.

The DNSc course has enabled me to become involved in other areas of research through partnership working with the Universities of Durham and York. Research into

cardiac disease and short term memory gave me the opportunity to present at the American Society of hypertension in New York in 2010. Although not directly linked with this study it has shown me the potential that a practicing clinician has to extend their research skills to other areas of research. This research has provided me with the opportunity to work with experienced researchers from a cross-section of academia, providing the clinical skills they needed to assist the facilitation of a new ground-breaking study that will continue into next year.

This experience is supported by other researchers into the professional doctorate. According to Benz and Shapiro (1998) the professional doctorate aims to provide students with the expert knowledge to inform practice, including evidence, evaluation, critical reflection, practice development and research to extend or modify existing knowledge. But practice development does hold some ambiguity in research and practice (Clarke and Procter 1999).

In practice research is not always seen as integral to normal working, with poor research resources available to organizations. Within my own organisation there is no research and development policy, very little funded research and understanding of the importance of research to everyday nursing practice. Promoting research within the organization will provide nurses and other health professionals with a basis on which to develop their own ideas, within their area of expertise.

Managers value audit, not research as a means to evidence based practice. I found that study leave was given as a luxury not as a need for clinical practice development. This is supported by Reed and Procter (1995) who found tensions for those clinicians who were trying to provide a clinical service and generate research. This culture of seeing research as the remit of external research providers, where practitioners are not accepted as researchers, but are only capable of being researched was something I experienced in the early part of the course. It has moved in recent times as my credibility within the organization has increased and my confidence to question practice has been accepted.

The absence of a research culture in primary care is not just present within my organisation, it is endemic nationally. According to Small (2003) it is not just financial or career structure constraints, but attributed to a lack of primary care practitioners with

research skills and the transferability of evidence from secondary to primary care. Returning to the research question for this study, 'Why do cardiac patients from lower socio-economic backgrounds not access phase 3 cardiac rehabilitation services?' I have been able to explore an issue that I felt needed further work both as a researcher and practitioner.

The study has enabled me to embark on journey with the participants that will have implications for my practice in the future. I hope through undertaking the DNSc I am able to promote research based practice within my organisation and encourage other nurses to reach their full academic potential. The course has allowed me to develop into a practitioner that is able to question, challenge and embrace practice in the future.

### **8.7 Peer Support**

As well as the clinical supervision provided by the cardiologist I gained much support from my peers within my team. I was able to give chapters to them for proof reading to ensure there were no spelling or grammatical errors. This was useful to me as the researcher, and to them to enable them to feel involved in my work. The team provided me with the names of possible participants from their patient caseload, discussing the research with the patient before I contacted them. Their understanding of the study and its aims and objectives gave them the skills to approach patients in an informed way.

As the DNSc is a professional qualification it is important to ensure the support of peers within the organisation to encourage examination and critical thinking in the work place. The researcher cannot work in isolation but needs to liaise with peers to cover study leave and provide resources for the study to happen. This is much more likely to happen within a team that fully understands the relevance of the study to the organisation and sees its worth in the management of long term conditions.

### **8.8 Summary**

This chapter has explored the personal journey I have undertaken since commencing the DNSc course in 2003. The reflective practice I first described in chapter one has been further examined through my personal insight. Research and practice are intrinsically linked within my role as a cardiovascular clinical team leader and I hope to

keep developing research skills in the future to promote service development within my organisation. The next chapter will conclude this phenomenological study and provide an overview of the research in relation to the research question.

## **CHAPTER 9 – CONCLUSION**

### **9.1 Introduction**

In this chapter some of the main issues of the research will be explored and summarised. The study into why patients from lower socio-economic backgrounds do not access phase three cardiac rehabilitation programmes, encompasses the patient journey from their cardiac event to their adjustment to normal living using a Heideggerian phenomenological approach. Within this journey illness perceptions and beliefs have been a significant factor as the means of coping with each stage of their recovery. The researcher's journey through the process has been explored, and within a DNSc the professional and personal development of her has impacted on the study. The significance of the findings for clinical practice and education in the future will be explored.

The study developed from a need for a better understanding of the complex needs and social expectations of socially deprived patients and appropriateness of cardiac rehabilitation programmes for them. Previous research shows very little qualitative work into patients from poor socio-economic and their barriers to accessing cardiac rehabilitation and involvement in service provision, with limited research into people with angina, post operative or revascularisation patients and cardiac rehabilitation. Physical barriers to accessing cardiac rehabilitation such as transport, age and cost that exist for socio-economically deprived patients are known from quantitative research, but an in-depth study was useful to explore issues qualitatively from the patients' perspectives.

### **9.2 Phenomenological perspectives of the study**

Heidegger's (1962) phenomenological approach influenced the design and implementation of the study. It has contributed to the understanding of the participants' experiences by exploring the concepts of 'Being' and 'Self'. 'Being' and 'Self' have been fundamental in the exploration of the participants' journeys from their cardiac event to adjustment to normal life. The Heidegger concept of truth is important for the researcher as a philosophical base on which to build the study. It is important for researchers to establish the truth of what has happened, to study participants through their experiences, beliefs and perceptions. The truth in this sense is subjective, but

nevertheless extrinsic in understanding the participant perspective, through their narrative.

This exploration of the concepts of 'Being', 'Self' and 'truth' within the study has allowed the author to develop her role from practitioner to researcher throughout the process. The study has highlighted some phenomenological aspects that will now be summarized.

### **9.2.1 Illness perception and health belief**

The participants all fully understood their cardiac diagnosis and what it meant for them in the long-term. They accepted the need for medical interventions and were grateful for the input of clinicians. The participants who felt they had a greater control on their recovery made better progress than those who felt it taken from them. The cardiac event had affected their 'Self' and worth within society. Pre-conceived ideas from family, friends or the media influenced the perceptions of the participants on the cardiac event. They tried to negotiate the event as non-cardiac such as indigestion or arthritis, or ignore it until it became too unbearable to tolerate. Media depiction of a heart attack as a piercing pain in the chest did not help their perceptions, as most did not experience classic cardiac symptoms. The pre-conceived idea about cardiac illness being an old persons' affliction was present in the participants' stories.

The participants perceived cardiac rehabilitation in a negative way. They felt that far from helping them recover it would have a detrimental effect on their recovery, slowing down their returning to normal daily living. They saw those that did attend as older people, with time on their hands who wished to talk about their illnesses and problems.

The cardiac events gave the participants a reality-check about the nature, purpose and meaning of their life. The study highlighted the importance of the grief and loss experiences of the participants. All had been shocked by their diagnosis and underwent a transition through grief processes, encompassing fear, shock, denial and anger before reaching acceptance of what had happened to them. This transformation, through to psychological coping and personal control of their lives was pivotal to their long-term life adjustment. The current timing of cardiac rehabilitation in this process does not take into account the needs of an individual to go through these processes.

In people from lower socio-economic backgrounds their financial and social arrangements are not secure, and their need to return to normal living is under a greater strain than for someone from a middle or upper class background. They do not receive the same sickness benefits as those in secure, high paid jobs or those independently financially secure. The need to return to work as soon as possible is essential as the social benefits they received were not enough to sustain their families.

### **9.2.2 Restoration of the Self**

The cardiac experience was viewed as a serious medical event that threatened the 'Being' and integrity of the participants in this study de-stabilising their everyday activities, amidst the fear and concern that there may be a re-event of their cardiac incident. Within the family they felt overprotected, had reduced functional abilities to continue with their previous roles and responsibilities or they felt isolated. Long-term life adjustment for the participants in this study involved the participants being able to re-establish their own control in their lives through informed choices about lifestyle changes and decisions about access to cardiac rehabilitation. Previous research has highlighted the need for family support towards aiding recovery after a cardiac event but this study found that participants could feel suffocated with the over-protection of loved ones.

The restoration of 'Self' for the participants was the ultimate goal for themselves to regain control and belief in their worth within their world. It enabled them to make long-term life adjustments after the cardiac event to regain their physical and psycho-social function within their environment for the future management of their illness without the perceived need for cardiac rehabilitation.

### **9.3 Implications for clinical practice**

Health care professionals involved in cardiac rehabilitation can help individuals to return to normal living following their cardiac event through a more holistic, multi-agency approach to their management. This involved better use of resources and providing a tailor-made, seamless service for patients and their carers. Currently there are four phases of cardiac rehabilitation, each stage is offered at specific times in the patient journey.



The National Service Framework for Coronary Heart Disease (Department of Health 2000) is now 10 years old and is currently being evaluated to establish its success in provision of cardiac services for the population. It was a prescriptive framework that gave health professionals targets and goals to be achieved in relation to cardiac rehabilitation, focusing on physical activity, advice, information and support. This though does not address the issue of improving uptake of cardiac rehabilitation in the hard to reach groups explored in this study, those from lower socio-economic backgrounds.

The Government publication, *Winning the War on Heart Disease: Progress Report* (Department of Health 2004) argued that there was a need for further improvements in the management of long term care of patients following a cardiac event. The recent White Paper, *Liberating the NHS* (2010) has asked that patients be more involved in their choices of care. This has implications in the involvement of the 'unheard' patient in service design and delivery. These are patients who do not access services so never have a voice in their development.

This qualitative, in-depth study into why people in lower socio-economic groups do not access cardiac rehabilitation provides health professionals involved in cardiac rehabilitation with an understanding of the issues that this group of patients have. By incorporating these findings into their decision-making and practice it will enable them to engage more effectively with patients, looking at ways of engaging them into accessing and developing services. Health professionals can help this group of patients by realizing their perceptions of their illness and their beliefs of the outcomes following a cardiac event.

Within the hospital setting cardiac rehabilitation teams can help promote cardiac rehabilitation by giving clear and simple information about their role and the purpose of cardiac rehabilitation. If possible the patient and their families could be invited to see a rehabilitation session in progress before their discharge. These teams need to differentiate from other nursing staff in the uniform they wear so patients are certain of their place in their health journey. Early assessment and identification of patients' beliefs about their illness would allow for timely interventions to deal with any prevailing misunderstandings that they might hold about their condition, treatment and future

behaviours. Cardiac rehabilitation can be discussed as an element of their care package.

Following discharge from hospital community cardiac nurse teams play a vital role in the patients continued road to adjustment. A review of the patients' health beliefs and perceptions of what has happened to them could be facilitated here to support the hospital team. Cardiac rehabilitation provision, offering a choice of programmes, a choice of times and tailor-made courses could be discussed. The patient can determine if, how and when they would access sessions and the most appropriate approach to them. This could be an evening session, one to one or a home based service with a facilitated physical activity and lifestyle components to significantly influence practical preventive lifestyle behaviours against illness recurrence and complications. These programmes would need to include objectives that would promote better understanding of some of the complex processes of the illness and its management using simple terms and language.

Instead of a four phase cardiac rehabilitation process health professionals could be innovative and develop a patient-centred rehabilitation programme that is not time specific but addresses the needs of the individual where they are in their 'adjustment to self'. This would enable patients to choose what they wanted from a menu of options. Self-management programmes could be introduced for those patients who would prefer to self-manage their illness with regular reviews either at home or within a clinic setting. These could be supported by the use of the current written material available, The Heart Manual, Angina Plan and Revascularisation plan.

To aid cardiac patients recover control of their lives again in the long term, it is essential that they are sufficiently equipped to deal with the challenges of self-managing their illness and recovery at home. Patients usually adopt a passive role in hospital setting, by virtue of the complex, technical treatment and care being provided. This non-active engagement by recipients of care in a professionally-controlled environment does not empower patients. They need to develop the necessary self-confidence and abilities required to take personal responsibility and control of their own recovery and health after hospital discharge. The sudden change of role expectations from being passive recipients of care to self-managers in their recovery and adjustment to the illness

becomes a challenge to both patients and health professionals. It intensifies patients' vulnerable state, non-compliance to advice and instructions about behavioural risk modifications or medication taking, leading to possible cardiac re-events and hospital re-admissions.

This cycle of passive involvement in the illness management and recovery process deprives cardiac individuals of acquiring the necessary skills, abilities and self-confidence to fulfill their obligations and responsibilities of self-management. They need support towards re-establishing their 'active selves again', encouraging them to be active 'processors' and 'theorisers' of their own condition, if a more patient-centred approach to cardiac recovery is to be promoted (Hirani & Newman 2005).

The self-empowering of patients through negotiation with them and the health professionals in the management of their condition and health improvement has benefits. Following discharge from hospital it gives them self-confidence, motivation and a better understanding about the cardiac illness to enable them to make a personal difference in their rehabilitation. To facilitate changes in the way cardiac rehabilitation is delivered, for it to succeed, there is a need to put educational programmes in place for health professionals. There is a need to change the traditional professional culture of 'doctors and nurses know best' and 'patients know least' when decisions about managing an individual's health are concerned. Health professionals need a greater awareness of personal, socio-cultural, economic, moral and ethical elements that shape the individual. Health professionals therefore must now listen to the needs of the individual and learn to accept that patients have an important personal responsibility in managing illness, through informed choices.

The contribution of this study to new knowledge uses a phenomenological approach to understand of the experiences of people from lower socio-economic groups in their decision not to access cardiac rehabilitation. Although this perspective provides one possible interpretation of the issue, there is a strong likelihood that other hidden possibilities may still exist that need further exploration. Replication of this study therefore is recommended with a larger sample to include key family members as well as other cultural and religious groups. This would widen the horizon of the investigation.

The implications of using a Heideggerian approach to service development enables health professionals understand and appreciate the benefits of participants' experiences to providing health services that address their needs. The study shows the participants' experiences and feelings following their cardiac event and through their health journey from the 'established self' to the 'threatened self' and towards the 'adjusted self' with the researcher's analytical interpretation of their contextual framework or 'Being'.

The Heideggerian approach focused on the participants' experiences and the processes they chose to cope with a cardiac event. It enables a better understanding of the patient journey and the choices individuals made during a challenging time in their life. It gives a subjective, unique insight into the feelings and behaviours of individuals following a life threatening event.

The study has a valid place in nursing research through its exploration of meanings of an experience, interpreting those meanings and informing practice from a qualitative perspective. Service development is predominantly based on quantitative data in a positivist paradigm. This study provides a basis for service development that is qualitative, based on the real life experiences of individuals who have had a cardiac event. It also gives an insight into the feelings and beliefs of individuals who have not accessed services, despite the severity of their event. The 'unheard' patient journey offers health care professionals an opportunity to re-visit services post NSF and re-design effective service provision for the future.

The use of other qualitative approaches to further extend the knowledge of patients' access to services would add to our current state of understanding. This could be extended to other long term conditions, such as people with diabetes, respiratory disease, strokes or peripheral vascular disease. Similar findings would increase our confidence in the conclusions drawn, or the discovery of other phenomena.

#### **9.4 Summary**

In conclusion, this study has explored the reasons why people from lower socio-economic backgrounds do not access phase three cardiac rehabilitation and put forward recommendations for the future development of these services for the benefit of all

patients, including the 'unheard', non-attendees. It has implications for the type of rehabilitation programmes offered and the information, support and care provided by cardiac rehabilitation teams and other health professionals.

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## **APPENDICES**

- Appendix A      Patient Journey and the 4 Rehabilitation Phases**
- Appendix B      Patient Information Booklet**
- Appendix C      Consent Form**
- Appendix D      Participant interview questions for the initial interviews**
- Appendix E      Training needs Analysis and Learning Plan for PGR Skills Training**



## Appendix A - Patient Journey and the 4 Rehabilitation Phases

### Phase One

Rapid access chest pain clinic  
(New angina patients)

Hospital admission with myocardial  
infarction (MI) heart surgery

### Phase Two

Home visits by Specialist Nursing Team. Patient contacted within 24 hours of discharge by telephone. Patient seen at home within five working days.

### Phase Three

#### *Group*

Structured rehabilitation programme  
2-4 weeks structure rehab programme

8 week programme covers exercise, relaxation,  
lifestyle changes and support.

#### *Home*

12 week programme  
(immediate start)

Did not attend → no action

### Phase Four

Maintenance - Patients take control of continuing their physical activity and maintaining lifestyle changes.

## Appendix B – Patient Information Booklet

# Uptake and Engagement in Cardiac Rehabilitation Services

## Research Study

### Patient Information Booklet

You are being invited to take part in a research study. Before you decide whether to take part or not it is important for you to read this information sheet about why the research is being done and what it will involve.

Please take time to read the following information carefully and discuss it with others if you wish.

Take time to decide whether or not you wish to take part.

Thank you for taking time to read this.

Ask us if there is anything that is not clear or if you would like more information.

***What is cardiac rehabilitation?***

Cardiac rehabilitation is a programme of care for people following a diagnosis of coronary heart disease or following heart surgery. It consists of physical activity sessions, lifestyle information, relaxation techniques and support. It can be done in a group setting or home based.

***What is the purpose of the study?***

To ask patients and their carers why they have not attended cardiac rehabilitation and what could be done to develop services that would help people to come to the rehabilitation programmes.

***Why have I been chosen?***

Because you have coronary heart disease and live in Darlington. There will be 20-30 patients taking part and 20- 30 carers taking part.

***Do I have to take part?***

It is up to you whether or not to take part. If you decide to take part you will be given this information sheet to keep and be asked to sign a consent form. If you don't want to take part it will not affect your care in any way.

***If I take part can I withdraw from the study?***

Yes, you are free to withdraw at any time and without giving a reason. A decision to withdraw or not to take part at all will not affect the standard of care you receive. Once you have withdrawn you can choose to return onto the study.

***What will happen to me if I take part?***

The research will be completed within 18 months, with patients being interviewed on a one to one basis. An audio-tape will be used to tape what is said. The information will then be written up.

The interviews will each last for up to one hour.

***What do I have to do?***

You will be asked questions about your experiences following a diagnosis of coronary heart disease. You will be asked questions about how you feel about cardiac rehabilitation and what services you would like to see develop.

***What are the possible benefits of taking part?***

The information we get from this study may help us to provide all patients with coronary heart disease with better rehabilitation services in the future.

***What happens when the research study stops?***

A report will be made available on the findings of the study, with recommendations for future service development.

***Will my taking part in this study be kept confidential?***

All information that is collected during the course of the research will be kept anonymous. Any information about you will have your name and address removed so you cannot be recognised from it.

***What will happen to the results of the research study?***

The research findings will be presented to the Primary Care Trust, Durham and Darlington acute Trust and the coronary heart disease voluntary group. If you participate you will be able to request a full copy or a summary of the study.

***Who is organising and funding the research?***

The researcher, Barbara Conway, is undertaking the research for her Doctorate in Nursing Sciences at the University of Northumbria, in partnership with Darlington Primary Care Trust and Durham and Darlington Acute Trust.

This information booklet is also available on cassette tape or CD.

**Contact: Barbara Conway**

Clinical Team Leader for Coronary Heart Disease Services.

NHS Darlington

Dr.Piper House

King Street

Darlington

DL3 16JL

Tel: 01325 746187

Email: [barbara.conway@nhs.net](mailto:barbara.conway@nhs.net)

## Appendix C – Consent Form

# Consent Form

Title of Project: Uptake and Engagement in Cardiac Rehabilitation Services

Name of Researcher: \_\_\_\_\_

Please initial box

1. I confirm that I have read and understand the information sheet for the above study and have had the opportunity to ask questions. ☐
2. I understand that my participation is voluntary and that I am free to withdraw any time, without giving any reason, without my medical care or legal rights being affected. ☐
3. I agree to take part in the above study. ☐

_____ Name of Patient	_____ Date	_____ Signature
_____ Name of person taking consent	_____ Date	_____ Signature
_____ Name of Researcher	_____ Date	_____ Signature

**April 2007 - Version Three**

Contact: **Barbara Conway**  
Clinical Team Leader for Coronary Heart Disease Services.  
NHS Darlington  
Dr.Piper House  
King Street  
Darlington, DL3 16JL  
Tel: 01325 746187  
Email: [barbara.conway@nhs.net](mailto:barbara.conway@nhs.net)

## **Appendix D - Participant interview questions for the initial interviews**

### **Box 1: Patient participant initial interview core questions**

*What has happened to you since you were told you had a heart condition?*

*How have you coped with your diagnosis?*

*What support have you had from family and friends?*

*What support have you had from nurses and doctors involved in your care?*

*What sort of changes has the diagnosis made to your everyday life?*

*What lifestyle changes have you tried to make?*

*What do you think cardiac rehabilitation is?*

*What concerns did you have about cardiac rehabilitation?*

*What concerns did you have about attending?*

*What might have made it easier to go?*

*What might have encouraged you to go?*

*Why do you think other people go?*

### **Box 2: The core questions for the initial carer focus group**

*How did you react to your partner's diagnosis of a heart condition?*

*What changes has the diagnosis made to your lives?*

*What lifestyle changes have you made?*

*What do you think cardiac rehabilitation is?*

*What did you feel about your partner's decision to either attend or not attend?*

*Do you feel you had any influence on their decision?*

*What concerns did you have about cardiac rehabilitation?*

*Were you included in the rehabilitation programme?*

*What are your views about the benefits of cardiac rehabilitation?*

*What developments would you like to see to help carers in the future?*

## Appendix E – Training Needs Analysis & Learning Plan for PGR Skills Training

PGR Student's name: Barbara Conway

Principal Supervisor's name: Sue Carr

Academic School:

Start date: September 2003

Mode: Doctorate in Nursing Sciences

### Skills Analysis

Skills areas	Proposal(s) for attaining skill or Evidence of attaining skill	Completion Date
<b>(A) Research Skills and Techniques - to be able to demonstrate:</b>		
1. The ability to recognise and validate problems	<i>Module AA113.</i> <ul style="list-style-type: none"><li>• <i>Manage and locate information relevant to coronary heart disease</i></li><li>• <i>Critically explore approaches to enquiry in the health, community and education areas</i></li><li>• <i>Explore political, ethical and professional contexts of enquiry</i></li><li>• <i>Evaluate the key philosophical principles underpinning knowledge exploration and generation</i></li></ul>	Jan 2004

2. Original, independent and critical thinking, and the ability to develop theoretical concepts	<p><i>Module AA113. Research skills, foundations and philosophies of enquiry.</i></p> <ul style="list-style-type: none"> <li>• <i>Critically appraise the range of approaches, e.g positivism, realism, and constructionist.</i></li> <li>• <i>Critical appraisal of research literature</i></li> </ul> <p><i>Thesis development</i></p>	<p>Jan 2004</p> <p>Nov 2010</p>
3. A knowledge of recent advances within one's field and in related areas	<p><i>Module AA113.</i></p> <ul style="list-style-type: none"> <li>• <i>Literature review of current research into cardiac rehabilitation</i></li> <li>• <i>Ongoing updates on literature searches</i></li> </ul>	<p>Jan 2004</p> <p>Nov 2010</p>
4. An understanding of relevant research methodologies and techniques and their appropriate application within one's research field	<p><i>Module AA113.</i></p> <ul style="list-style-type: none"> <li>• <i>Studied positivism, descriptive approaches, participatory research, post-modern approaches, constructivism, interpretivism, phenomenologist research, Grounded theory, systematic reviews and concept analysis</i></li> </ul> <p><i>Module AA114. Research skills, design and method</i></p> <ul style="list-style-type: none"> <li>• <i>Introduction to statistical analysis with SPSS</i></li> <li>• <i>Thesis development</i></li> </ul>	<p>Jan 2004</p> <p>Feb 2004 Nov 2010</p>





<b>(B) Research Environment – to be able to:</b>		
1. show a broad understanding of the context, at the national and international level, in which research takes place	AA 117 Module – Research skills: Management and Governance <ul style="list-style-type: none"> <li>• Critical exploration of National and international research agendas</li> </ul>	Feb 2005
	AA119 Module – Practice development. The context of the organisation <ul style="list-style-type: none"> <li>• To critically engage with the nature of development and research cultures</li> <li>• Exploration of research strategies at a National level</li> </ul> Attend National and International conferences to present current practice and research	June 2005  April 2005, March 2007, June 2007, October 2010
	AA 113 Module – Research skills. Foundations and philosophies of enquiry. <ul style="list-style-type: none"> <li>• Ethical review and issues in health care research</li> </ul> AA 114 Module – Research skills, designs and methods <ul style="list-style-type: none"> <li>• Developing a research question</li> </ul> AA 117 Module – Research skills: Management and Governance <ul style="list-style-type: none"> <li>• Examine the impact of research governance frameworks on the conduct of research studies.</li> <li>• Articulate the skills required to negotiate with funders and stakeholders to gain access to research populations</li> </ul> AA 120 Module – Knowledge Domain Integration <ul style="list-style-type: none"> <li>• Ethical approval</li> <li>• Developing research proposals</li> </ul> Research proposal	Feb 2004  Jan 2004  Feb 2005  May 2005 June 2005 July 2005 Sept 2005

	<ul style="list-style-type: none"> <li>• <i>University ethics panel</i></li> <li>• <i>LREC study day</i></li> </ul>	March 2007 Sept 2006
	<ul style="list-style-type: none"> <li>• <i>NHS research Governance Committee</i></li> <li>• <i>LREC approval</i></li> </ul>	June 2007 July 2007
3. demonstrate appreciation of standards of good research practice in their institution and/or discipline	<i>AA 119 Module – Practice development: The context of the organisation</i> <ul style="list-style-type: none"> <li>• <i>Assignment to analysis the research and development culture of an organisation, exploring the Primary Care Trust and acute trust I work with</i></li> <li>• <i>Accepted onto research governance committee as a member</i></li> </ul>	June 2005  May 2008
4. understand relevant health and safety issues and demonstrate responsible working practices	<i>AA117 Module – Research skills: Management and Governance</i> <ul style="list-style-type: none"> <li>• <i>Examine the impact of research governance frameworks on the conduct of research studies</i></li> </ul> <i>AA118 Module – Nursing Practice: Health care need and health care provision</i> <ul style="list-style-type: none"> <li>• <i>Conceptualise clinical governance within service user perspectives</i></li> </ul> <i>AA119 Module – Practice development: The context of the organisation</i> <ul style="list-style-type: none"> <li>• <i>Exploration of research strategies locally and nationally</i></li> </ul>	Feb 2005  June 2005  June 2005
5. understand the processes for funding and evaluation of research	<i>AA118 Module – Nursing Practice: Health care need and health care provision</i> <ul style="list-style-type: none"> <li>• <i>Develop a 'bid' for a project using the Rowntree Foundation template.</i></li> </ul> <i>Involvement in developing research bids as part of my managerial role within my organisation</i>	June 2005  Ongoing

6. justify the principles and experimental techniques used in one's own research	AA113 Module – <i>Foundations and philosophies</i>	Jan 2004
	<ul style="list-style-type: none"> <li>• <i>Examined research methodology</i></li> </ul>	
	AA 120 Module – <i>Knowledge domain integration</i>	Sept 2005
	<ul style="list-style-type: none"> <li>• <i>Explored nature and purpose of research area</i></li> <li>• <i>Critically evaluated research methodologies in relation to own study</i></li> <li>• <i>Develop and apply appropriate research design</i></li> <li>• <i>Engaged with relevant literature in relation to own study</i></li> </ul>	
7. understand the process of academic or commercial exploitation of research results		Nov 2007
	<ul style="list-style-type: none"> <li>• <i>Development of project steering group to oversee core research thesis</i></li> </ul>	
		Nov2010
	<ul style="list-style-type: none"> <li>• <i>Thesis writing</i></li> </ul>	
7. understand the process of academic or commercial exploitation of research results	AA118 Module - <i>Nursing Practice: Health care need and health care provision</i>	June 2005
	<i>Presentation of research at conferences (poster)</i>	Nov 2007, Feb 2008, June 2009
<b>(C) Research Management – to be able to:</b>		
1. apply effective project management through the setting of research goals, intermediate milestones and prioritisation of activities	<ul style="list-style-type: none"> <li>• <i>Time management of assignments and reached expected goals within agreed timescale</i></li> <li>• <i>Gantt chart used for research timetable</i></li> <li>• <i>Within clinical setting constantly involved in project management within given milestones</i></li> <li>• <i>Effective facilitation of the National Service Framework for coronary heart disease within primary care, and reaching relevant milestones and goals.</i></li> <li>• <i>Project steering group facilitation</i></li> </ul>	Ongoing
2. design and execute systems for the acquisition and collation of information through the effective use of appropriate resources and equipment	<ul style="list-style-type: none"> <li>• <i>Training in 'Endnote' reference management</i></li> <li>• <i>Template for reflective practice</i></li> <li>• <i>Sampling matrix development</i></li> </ul>	Nov 2005 April 2006 March 2006

3. identify and access appropriate bibliographical resources, archives, and other sources of relevant information	<ul style="list-style-type: none"> <li>• <i>Website search engines</i></li> <li>• <i>Use of library facilities online and ordering relevant reading material</i></li> <li>• <i>Use of action learning smart group</i></li> </ul>	Ongoing
use information technology appropriately for database management, recording and presenting information	<ul style="list-style-type: none"> <li>• <i>Spreadsheet, word, PowerPoint, use of 'Endnote' all proficient</i></li> </ul>	As part of nursing role through PCT
<b>(D) Personal Effectiveness – to be able to:</b>		
1. demonstrate a willingness and ability to learn and acquire knowledge	<ul style="list-style-type: none"> <li>• <i>All assignments submitted at agreed time and passed</i></li> <li>• <i>Keep up to date with new research through search engines</i></li> <li>• <i>Attend relevant training courses at work appropriate to the research element of the doctorate e.g COREC conference</i></li> <li>• <i>Clinically work within a CPD driven career development framework where lifelong learning central to own professional competence.</i></li> </ul>	Ongoing
2. be creative, innovative and original in one's approach to research	<ul style="list-style-type: none"> <li>• <i>Using action research for study requires creativity, innovation and originality. Keeping up to date with current action learning research and new ways of planning and implementing the research into clinical practice.</i></li> <li>• <i>Have extensive experience in planning, developing and evaluating cardiac rehabilitation projects including rehabilitation for people with angina and a 'Get Fit For Your Op' programme for people waiting for cardiac surgery.</i></li> </ul>	Ongoing
3. demonstrate flexibility and open-mindedness	<ul style="list-style-type: none"> <li>• <i>Work within the NHS at a senior management level whilst maintaining clinical caseload requires flexibility and open-mindedness.</i></li> </ul>	Ongoing
4. demonstrate self-awareness and the ability to identify own training needs	<ul style="list-style-type: none"> <li>• <i>Annual Personal development plans are developed with line manager to identify training needs.</i></li> <li>• <i>Professional portfolio is kept up to date in line with NMC requirements.</i></li> </ul>	Ongoing

5. Demonstrate self-discipline, motivation, and thoroughness	<ul style="list-style-type: none"> <li>• <i>As a clinical team leader with a large individual caseload with minimal supervision, experienced in managing own time, the teams workload, self discipline and motivation for own work and others.</i></li> <li>• <i>Working within study leave constraints to effectively initiate and develop research study</i></li> </ul>	Ongoing
6. Recognise boundaries and draw upon/use sources of support as appropriate	<ul style="list-style-type: none"> <li>• <i>Currently work within a system of peer support and clinical supervision.</i></li> <li>• <i>Monthly action learning sets with other clinical team leaders in the PCT</i></li> <li>• <i>Bimonthly action learning sets with fellow DNSc students.</i></li> </ul>	Ongoing
7. Show initiative, work independently and be self-reliant	<ul style="list-style-type: none"> <li>• <i>Senior clinician status demands the ability to show initiative, work independently and be self-reliant.</i></li> <li>• <i>Developed new services that first in country and are used as an example of good practice nationally and internationally e.g Angina rehabilitation programme, 'Get Fit For Your Op'</i></li> </ul>	Ongoing
<b>(E) Communication Skills – to be able to:</b>		
1. Write clearly and in a style appropriate to purpose, e.g. progress reports, published documents, thesis	<ul style="list-style-type: none"> <li>• <i>Completed the taught component of the DNSc, this was assignment based throughout.</i></li> <li>• <i>Midpoint progression report</i></li> </ul>	Sept 2006 Nov 2009
2. Construct coherent arguments and articulate ideas clearly to a range of audiences, formally and informally through a variety of techniques	<ul style="list-style-type: none"> <li>• <i>As a senior clinician regularly involved in formal and informal training for nurses, doctors and other allied health professionals</i></li> <li>• <i>Facilitate information sessions for voluntary groups and member of the public about heart disease</i></li> </ul>	Ongoing

3. Constructively defend research outcomes at seminars and viva examination	AA118 Module – Nursing Practice <ul style="list-style-type: none"> <li>• <i>Presentation to peers and tutors based on research study ideas</i></li> <li>• <i>Monthly supervision</i></li> <li>• <i>Present at National conference for cardiac rehabilitation findings of the research</i></li> </ul>	June 2005  Ongoing  October 2010
4. Contribute to promoting the public understanding of one's research field	<ul style="list-style-type: none"> <li>• <i>As a senior clinician effective at promoting understanding of heart disease at conferences, seminars, voluntary group meetings and within the press locally, nationally and internationally.</i></li> </ul>	Ongoing
5. Effectively support the learning of others when involved in teaching, mentoring or demonstrating activities	<ul style="list-style-type: none"> <li>• <i>As a team leader effective in developing and implementing induction programmes for new staff</i></li> <li>• <i>Mentor student nurses and teach them about heart disease during their placement within the team</i></li> <li>• <i>Ensure team members keep up to date with mandatory and professional training and development</i></li> <li>• <i>Active in training staff how to use equipment safely and effectively</i></li> <li>• <i>Give regular training sessions to nurses and doctors about heart disease management.</i></li> <li>• <i>Published paper in the Advanced cardiology nursing Journal (April 2005)</i></li> </ul>	Ongoing
<b>(F) Networking and Team working - to be able to:</b>		
1. Develop and maintain co-operative networks and working relationships with supervisors, colleagues and peers, within the institution and the wider research community	<ul style="list-style-type: none"> <li>• <i>Monthly supervision with the University with supervision team</i></li> <li>• <i>Regular contact via email with supervisors</i></li> <li>• <i>Two weekly team meeting with clinical team</i></li> <li>• <i>Monthly one to one with clinical mentor</i></li> </ul>	Ongoing

	<ul style="list-style-type: none"> <li>• <i>Action learning sets within clinical practice with other clinical leaders and University with peers</i></li> <li>• <i>Work as a member of the cardiac network board to improve and share practice within clinical role</i></li> <li>• <i>Chair the local planning and implementation group for coronary heart disease within the PCT</i></li> <li>• <i>A member of the Local network of cardiac care group for Durham, working with primary and secondary care to develop new initiatives</i></li> <li>• <i>Research governance committee member</i></li> </ul>	
2. Understand one's behaviours and impact on others when working in and contributing to the success of formal and informal teams	<ul style="list-style-type: none"> <li>• <i>Completed a leadership course that has involved Myer Briggs personality testing. This has enabled me to improve my management skills</i></li> <li>• <i>Work clinically in area with clearly defined professional conduct requirements according to the NMC.</i></li> <li>• <i>Have the ability to communicate effectively from academic and clinical settings to a group of people from the general population.</i></li> </ul>	<b>Ongoing</b>
3. Listen, give and receive feedback and respond perceptively to others	<ul style="list-style-type: none"> <li>• <i>Annual appraisals are facilitated by me for team members, followed up by a six monthly update.</i></li> <li>• <i>Annual report submitted to the PCT board about coronary heart disease management</i></li> <li>• <i>Annual focus groups and regular questionnaires for patients to have a say on the service development of the rehabilitation programmes.</i></li> <li>• <i>Regular QOF (Quality outcome framework) data examined.</i></li> <li>• <i>As a senior clinician advice and information is constantly being sought locally and nationally about heart disease management.</i></li> </ul>	Ongoing



<b>(G) Career Management - to be able to:</b>		
1. Appreciate the need for and show commitment to continued professional development	<ul style="list-style-type: none"> <li>• <i>Annual appraisal and personal development plan outlines professional development needs.</i></li> <li>• <i>Undertaking leadership course</i></li> <li>• <i>Attend relevant conferences, seminars and training sessions as appropriate.</i></li> </ul>	Ongoing
2. Take ownership for and manage one's career progression, set realistic and achievable career goals, and identify and develop ways to improve employability	<ul style="list-style-type: none"> <li>• <i>Working within the NHS has enabled career progression over the years through experience and relevant professional training and personal development.</i></li> <li>• <i>Continuously set career goals that are realistic and achievable within the current climate of change in the NHS.</i></li> <li>• <i>Keep up to date with current thinking, evidence based practice and academically continue to set challenges that are appropriate for current practice and future professional development.</i></li> </ul>	Ongoing  Ongoing
3. Demonstrate an insight into the transferable nature of research skills to other work environments and the range of career opportunities within and outside academia	<ul style="list-style-type: none"> <li>• <i>As a clinician the research skills learnt within the academic environment are transferred into practice to improve patient care.</i></li> <li>• <i>Constantly involved in collecting and collating data that can be used as evidence based practice in a clinical setting.</i></li> <li>• <i>The research currently underway for the DNSc will have a direct impact on the nursing care of people with heart disease and chronic disease management.</i></li> </ul>	Ongoing
4. Present one's skills, personal attributes and experiences through effective CVs, applications and interviews	<ul style="list-style-type: none"> <li>• <i>As a clinician, keep CV up to date.</i></li> <li>• <i>Previous applications and interviews have required expertise knowledge and a presentation to demonstrate skills required for the role.</i></li> </ul>	Ongoing

List of courses/seminars/modules/activities to be completed/attended

<b>Course/seminar/module/activity to be completed/attended</b>	<b>Description of course/seminar/module/activity to be completed/attended</b>	<b>Date</b>
Doctorate in Nursing Sciences (DNSc)	<ul style="list-style-type: none"> <li>• 2 years taught, modular with assignments to complete. Completed in September 2005</li> <li>• Research phase – monthly supervision</li> </ul>	Sept 2005  Ongoing
PGR training sessions	<ul style="list-style-type: none"> <li>• Writing a thesis</li> </ul>	When available
Action research	Attend action research courses/seminars	As available
Conferences	Attend/present to relevant conferences	
Philosophy and action research training	As available	

**Would like to attend some formal lectures within University that applicable to action research but I am limited due to study leave (21/2 days a month) and clinical workload. I will be requesting more study leave in my next appraisal at work.**